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ABSTRACT

This document presents the text of the Congressional hearing called to discuss the provision of health care services to people with Acquired Immune Deficiency Syndrome (AIDS) outside of hospitals, including home health care, hospice care, nursing home care, personal care and counseling, and other support services for patients and their families. Opening statements are included from Congressmen Henry Waxman and James Scheuer. Under assumed names, a husband and wife who have provided hospice services to AIDS patients in their home testify about nonhospital care for AIDS patients. Drew Altman, Robert Wood Johnson Foundation, describes a major new AIDS health services program. John Kelso, Health Resources and Services Administration (HRSA), United States Department of Health and Human Services, describes how the HRSA disseminates information on AIDS to the health care providers and the beneficiary populations of HRSA programs. Elmer W. Smith, Health Care Financing Administration, explains two groups of waivers which already exist under the Medicaid Program. Bevlyn Matthews, manager of patient care services, Transamerica Occidental Life Insurance Company, gives an overview of how her company's patient care services program operates and describes three recent AIDS case histories and how they were handled. Melvin Rosen, executive director of AIDS Institute, New York State Department of Health, presents New York's proposed comprehensive program for helping AIDS patients. Prepared statements and materials submitted for the record by the Department of Health and Human Services are included. (NB)

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NONHOSPITAL CARE FOR AIDS VICTIMS

ED289102

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

OF THE

COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

MARCH 5, 1986

Serial No. 99-137

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CONTENTS

Testimony of:	Page
Altman, Drew E., Ph.D., the Robert Wood Johnson Foundation	10
Kelso, John, Acting Administrator, Health Resources and Services Administration, Department of Health and Human Services	29
Martin, Edward, Acting Deputy Administrator, Health Resources and Services Administration, Department of Health and Human Services	29
Matthews, Bevlyn, R.N., manager of patient care services, Transamerica Occidental Life Insurance Co	126
Rosen, Melvin, executive director, AIDS Institute, New York State Department of Health	141
Smith, Elmer W., Director, Office of Eligibility Policy, Bureau of Eligibility, Reimbursement and Coverage, Health Care Financing Administration, Health and Human Services	38
Smith, Jane (assumed name), Baltimore, MD	4
Smith, John (assumed name), Baltimore, MD	4
Wren, Robert, Director, Office of Coverage Policy, Health Care Financing Administration, Health and Human Services	38
Material submitted for the record by Department of Health and Human Services:	
HCFA Guidelines for States Applying for Freedom of Choice Waivers Under 1915(b) of the Social Security Act	79
HRSA Proposal for Development of Service Delivery Demonstration Models for AIDS	49
Preliminary Estimate of the Impact of AIDS on the Medicare Program	70
Report: "Explaining What Factors Contribute to the Differences Between the CDC Estimate and the HCFA Estimate"	115

NONHOSPITAL CARE FOR AIDS VICTIMS

WEDNESDAY, MARCH 5, 1986

HOUSE OF REPRESENTATIVES,
COMMITTEE ON ENERGY AND COMMERCE,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
Washington, DC.

The subcommittee met, pursuant to call, at 9:45 a.m., in room 2322, Rayburn House Office Building, Hon. Henry A. Waxman (chairman) presiding.

Mr. WAXMAN. The hearing of the subcommittee will be in order.

This subcommittee has held a number of hearings on acquired immune deficiency syndrome. We have discussed AIDS research budgets, the safety and adequacy of the blood supply, the Public Health Service's response to AIDS, and AIDS treatment and research. Most recently, we began a series of hearings on the cost of AIDS care and who would pay for such care.

Today's hearings are the second in that series. Today we will discuss the provision of health care services to people with AIDS outside of hospitals. Such services include home health care, hospice care, and nursing home care, personal care and counseling, and other support services for patients and their families.

These services are important in AIDS care for three reasons. First and most obvious, they are more humane and more compassionate than institutional services can possibly be. As we have begun to see in hospice programs under Medicare, people who are seriously ill and certainly people with terminal illnesses are often better served outside high technology medical centers and in their own homes. While periodic hospital stays are often necessary, people with AIDS need not be relegated to intensive care for the rest of their lives.

Second, these services save money for all concerned. At our last hearing, the Centers for Disease Control testified that the average national cost of hospital and medical care for a person with AIDS from diagnosis to death was as high as $147,000. Since that time, other studies of nonhospital models have reported averages as low as $29,000, a difference of $118,000 per person. If the epidemic continues at its present rate, by next year at this time there will be over 17,000 new cases of AIDS in the United States. The possible savings from alternate care for these cases alone are over $2 billion.

Finally, the services provided in the home by family members or by health professionals and dedicated volunteers clearly illustrate the message the Public Health Service has tried to communicate to the country for years now: AIDS is not an easily spread disease.

With basic precautions about blood and body fluids, parents can safely care for their children, roommates can safely continue to live together, and health careworkers can safely work with patients.

For humanitarian, economic, and public health reasons, alternate care makes sense. But, however much sense it makes, it is unavailable to many people with AIDS because of limitations in financing systems. AIDS has brought out some of the worst and the best of the American health care system. We have sometimes paid dearly for inadequate and discriminatory care. We have often seen uninsured people forced to forgo needed care or face bankruptcy to obtain it. But we have also begun to learn about dignified illness among families and loved ones and about death foreseen and accepted.

I hope that today's hearings can begin to make our health care system work for Americans with this dreadful disease.

I would like to recognize any member who wishes to make an opening statement.

Mr. Scheuer, I would like to recognize you at this time.

Mr. SCHEUER. Mr. Chairman, I want to congratulate you and commend you on these series of hearings on AIDS. We are touching on an extremely sensitive and emotionally laden issue that affects people in a wide variety of ways. But it is an issue that we must face up to.

We have approximately 15,000 AIDS patients now, but it seems to be on a track where the patient count doubles every year. This is an exponential rate of increase. There may be 1 to $1^{1}/^{2}$ million people with the AIDS virus, some percentage of whom, whether it's 5 or 10 or 20 percent, we don't ultimately know, who will ultimately come down with AIDS.

The importance of the AIDS phenomenon is underlined by the fact that most AIDS victims are young and in the prime of their lives. It is further underscored by the fact that it is virtually always fatal.

You have hit on the problem of cost. We have heard figures bandied about from anywhere from $20,000 to $200,000. We have to face up to tough cost questions. We have to understand that we are not now in an era where we can do everything. We know we can do anything, but we also know we can't do everything. We have to make hard decisions.

We know that every time we spend $1 for one type of health care, we are, in effect, saying that $1 is not available for another type of health care; and it's not available for pressing needs outside of the field of health, for pressing education needs, and other very deeply needed compassionate needs of the American people.

When we spend money on AIDS, it means we are not spending money on preventive health counselling. We are not spending money on prenatal care for low-income mothers who urgently need that, postnatal care for infants. We have tough options, and we are going to have to make some very difficult, very hardheaded cost and benefit analyses to see where our precious health dollars are going to be spent.

We are spending about 12 percent of our total GNP for health care. This is more than any other country in the world spends. It is

not clear at all that we are giving our people the best health care in the world. And superimposed on this 12 percent now comes the additional burden of AIDS, the whole AIDS phenomenon, which, as I mentioned and as Congressman Waxman mentioned, is going off the chart and off the wall if we can't find an antidote.

We are going to have to find ways, especially when it is determined that the disease is in an advanced form and will be fatal. We are going to have to find ways of treating that patient in a sensitive, compassionate, caring way and yet reducing some of the extraordinary costs that have been attendant upon the treatment of AIDS patients in tertiary hospitals with all of the application of high tech means to extend life and prolong life.

Our society is going to have to face up to the awful heart-rending, painful question of whether, when a person has a fatal disease on a cost-benefit basis, it is worth it to that patient and worth it to society to spend the amount of dollars that are involved in the last days and weeks and perhaps months of AIDS treatment to extend life those last painful months when it's perfectly clear that it is a terminal situation.

These are decisions involved that are encapsulated by the word triage. We hate to play God. We hate to make these awful, painful, heart-rending triage decisions, yet mankind has been doing it for 5,000 years of recorded human history. The only difference now is that the tremendous leap forward, a quantum jump in high tech scientific ability to extend life, painful and depressing as it is, when the end is near in any event, at tremendous cost faces us with questions of triage we never had to face before.

I commend you, Mr. Chairman, again for holding these hearings and perhaps clarifying the issues and, even if not providing the final answer, at least leading us down the road to where we can see the elements in the debate and where the possible answers appear to be reconcilable and analyzable and available to caring human beings and to caring Congressmen.

Thank you.

Mr. WAXMAN. Thank you very much, Mr. Scheuer.

Our first two witnesses on the panel were two who are familiar with giving care to AIDS patients outside of a hospital setting. We had scheduled Mrs. Murray Sherman, whose daughter has AIDS. Unfortunately, her daughter has taken a turn for the worse, and Mrs. Sherman is not going to be able to be with us this morning.

Mr. John Smith is with us. He is from the Baltimore area. We would like to ask Mr. Smith and his wife to come forward at this time and take a seat by the microphone.

We welcome you today to this hearing. We are pleased that you were willing to come and talk about the kind of care that you have been involved with for AIDS patients. We can see it as one of a number of different models that we might well follow in other places in trying to deal with the health care needs of these patients who are very, very sick and unfortunately in every single instance we expect would die from the illness even though they are young in years.

I would like to hear from you at this time. If you would, just pull the microphone right up to you.

STATEMENT OF JOHN SMITH AND JANE SMITH (ASSUMED NAMES) BALTIMORE, MD

Mr. JOHN SMITH. Thank you very much.

I used the names "John Smith" and "Jane Smith" because in our area the issue of AIDS is a highly emotional one. Quite frankly, I fear for the health and well-being of my children, not from the standpoint of the disease but from the standpoint of those that don't understand and have a lot of feelings about it.

We have been doing hospice for 2½ years. We have had four persons live with us, three of whom died with us. The first patient that we had, lived with us for 13 months. He became essentially a member of our family. He had cancer. He was supposed to have died in the first month of his stay with us. He was indigent. He was without family. He was without home. In the Baltimore area we have a number of hospitals that provide hospice. What they don't provide is the care giver or the family or the group who care for these people.

My personal opinion is that persons that are terminally ill, the quality of their life is best in the context of family.

We have had three AIDS patients live with us, two of whom died. Their needs are the same as any human's needs for care and for persons around them that live a normal life. We have two children within the house. We live as family with these people.

A year ago the State of Maryland had a program that they call Project Home. It was designed for persons that have been in mental institutions. They have taken and are using it for hospice now, basically for persons with AIDS. Their program came about because of a man by the name of Robert Doyle. Robert was an indigent person that had AIDS. He was rejected by his friends. His family was thousands of miles away. He ended up in a motel room where nobody would care for him. The employees of the motel refused to clean the room or have anything to do with him. The media picked it up and justifiably pointed out the fact that this man is dying, has no place to live. We heard of that and decided to take him into our family.

The cost, the State pays $930 a month, of which about $75 a month goes to the personal needs of the individual. The State also contracts with a visiting nurses association to provide in-home nursing care and personal care for the individuals where needed.

The family provides the care, we provide home. We provide care for his body. We have also helped to provide spiritual care. There are volunteers that we get that come in and act as counselor and personal friend to the individuals.

So, from a cost standpoint it's the cheapest way to go. From a humanitarian standpoint and Christian standpoint, it provides the person with a place to live his life while he is dying.

I think we spend a lot of time forgetting the fact that this is something we are all going to do. I know for myself I look at other human beings and their plight. I say: Now, but for the grace of God go I. And indeed my mortality, I am very much aware of it.

Thank you.

Mr. WAXMAN. Thank you very much.

I certainly want to express my commendation to you and your wife for the fact that you are willing to give of your home and your time and your love for these people who are dying and to make a home for them in their final days.

How did you get involved originally in providing hospice care for AIDS patients?

Mr. JOHN SMITH. This is something you should tell.

Mrs. JANE SMITH. We heard and read about Robert Doyle, who was the patient that had no family, no home. It seemed to make a big hit in the Baltimore area. We decided that we would go to Johns Hopkins and find out exactly what AIDS was or was not.

Dr. Polk and his assistant Lois Eldrid spent a great deal of time making sure that the rumors were separated from the facts. The next day, after meeting with them, they called and informed us that Robert Doyle was out on the streets again and would we please help him. We did accept Robert Doyle.

At that time Project Home was not in assistance, which meant that we would have to carry Bob financially. It wasn't until Robert Doyle actually made the news that Project Home seemed to be getting more involved.

Our helping with Robert Doyle was strictly one of compassion, not wanting to see the man on the street. Getting involved with him and seeing exactly what the disease was doing led us into saying: Yes, we will do this again and again and again.

We have indeed had three AIDS patients that have died in our home, most of which have followed the same path. But they have all come to be part of the family. They have all been very much against nursing home facilities, not that the nursing homes would accept them anyway at that time. The nursing homes aren't really equipped, either. They are not equipped to handle the terminally ill. They are there for the aged.

Mr. WAXMAN. You are paid by the State of Maryland for providing this care?

Mrs. JANE SMITH. At this point in time if a patient is plugged into the system all ready with his social worked and everything when he comes to us, then things run pretty smoothly. Indeed Project Home provides the $900 a month; $75 goes into the patient's pocket, that is pocket money, a month for him to be able to still continue to be a human being that can go out and purchase things himself. The rest of it is strictly spent on patient care.

Mr. WAXMAN. Under what auspices does the patient get $900 a month?

Mrs. JANE SMITH. This is under Project Home.

Mr. WAXMAN. Is that part of the Medicaid Program in Maryland, do you know?

Mr. JOHN SMITH. What has happened, Project Home was originally designed for mentally ill, in other words, taking those persons that are in mental institutions and putting them in homes so that they can be deinstitutionalized. Maryland calls it medical assistance. This is where all their medical costs are cared for.

Mr. WAXMAN. So, it is the State of Maryland funding for AIDS patients and for mentally ill patients, to some extent, and they provide $900 a month for the care of these patients.

Mr. JOHN SMITH. Right. Part of that is SSI, supplemental security income. And I believe the State of Maryland makes up the rest of it. This $900, they have three levels of care. All AIDS patients have been going into the third level. In fact, I think the one, the fellow we have with us now will probably be put back to level two because he's better. Until he gets sick again, the level of care that he gets is less, needfully less than those that are sick.

Mr. WAXMAN. If he gets better, does that mean he gets less than $900?

Mr. JOHN SMITH. Yes. Well, what happens is they make the check out to him. Then we have an agreement that he signs it over to us. How it works out in the practical standpoint is slightly different. For instance, this individual who lives with us now is a spendthrift. So, he and I have agreed that I will dole his money out to him $25 a week.

Mr. WAXMAN. Is the money based on SSI disability or is it based on Medicaid eligibility for health care services, if you know?

Mr. JOHN SMITH. Disability, I think.

Mr. WAXMAN. The disability allotment for that individual.

Mr. JOHN SMITH. Right.

Most of the people we have had with us have not held jobs or have been marginally employed. Their Social Security is almost nonexistent other than the SSI.

Mr. WAXMAN. As I understand it, there is State money as well as SSI and it's a program for funding that is unique to the State of Maryland, where they are trying to allow for some kind of services for patients that are deinstitutionalized.

Mr. JOHN SMITH. Yes. That's right.

Mr. WAXMAN. Let me call on my colleagues and have them ask you some questions.

Mr. Whittaker.

Mr. WHITTAKER. Thank you, Mr. Chairman.

How many years have you been providing the service within your own home?

Mr. JOHN SMITH. Two and a half.

Mr. WHITTAKER. Two and a half. Have you——

Mr. JOHN SMITH. Before that, we provided shelter.

Mr. WHITTAKER. Has your example been picked up by either the media or others within your community that have admired your courage of opening your home?

Mr. JOHN SMITH. Frankly, it is a highly emotional issue. Even hospice, just cancer cases, we've kept a low profile because we don't want our children singled out and ridiculed. And that has happened in that area.

Mr. WHITTAKER. So, you're not actually aware that any other family in the greater metropolitan area in which you live have duplicated your example.

Mr. JOHN SMITH. Well, Project Home now has three care givers, two within Baltimore City and us within the area, doing this.

Mr. WHITTAKER. The other two that are participating weren't necessarily then from emulating your example. They were developed independently.

Mrs. JANE SMITH. They were developed independently.

We now, through Project Home, all the care givers, which are three separate families, are meeting at our house once a month for support of each other so that we can discuss what goes on with the different patients and how to handle them. It is a pilot project, and it still has some pitfalls.

A lot of the people, since they are taking in an AIDS patient, two of them, I think, were nursing assistants at a nursing home; so they have some experience. But living with an AIDS patient is quite different. So, they are learning still.

What they get from us is basically experience behind us. But it is through Project Home and a social worker that they have actually gotten involved. It is not through actually knowing us.

Mr. WHITTAKER. Have you been able to perceive in the last 2½ years that you have been participating in the program that the public attitude has somewhat shifted to one of a little more understanding?

Mrs. JANE SMITH. In some cases, but there are still—for instance, operating room nurses that I know personally are very upset with AIDS patients and don't seem to know as much medically about them as we know from living with them.

We do have problems within family, as far as our own relatives that will not visit.

The media at one point, not knowing any more than the rest of us knew, seemed to blow it a little more out of proportion than what needed to be. So, unfortunately, there are those that don't come back and later get the facts and say: OK, I've changed my mind and it's OK.

We only have actually one neighbor in our block that knows what we do. The others are not informed of what goes on in our house.

Mr. WHITTAKER. Thank you.

Mr. WAXMAN. Thank you, Mr. Whittaker.

Mr. Scheuer.

Mr. SCHEUER. Well, I must say I am sure we have all been deeply touched and very much impressed by the story you have told us. You are two really quite terrific people.

The question is, we are here sitting as a congressional committee. This is our learning mechanism. We hope to pick up enough knowledge and insights from hearing witnesses like you to construct national programs. This certainly is a national problem. We may have 15,000 AIDS patients this year and perhaps 30,000 next year and 60,000 the year after that and maybe 125,000 or so after that. The numbers mount rapidly.

But for the first 4 or 5 years the approach of caring for people in private homes could be, could be a manageable one. The question is, Are you two people so unique and are your characteristics, apart from compassion and caring and general intelligence, so spectacularly above average that what you have done is not susceptible of replication.

It may well be that you are two pretty unique people and that there are an infinitesimal handful of people like you around the country, if any. Or it could be that you could tell us: Well, whatever we are, we think the program, this kind of program could be widely adapted and that there are a lot of elderly people living

alone in homes where the kids have grown up, gone to school. They are empty-nesters, so to speak. And where, with a little intelligence, perhaps a little counseling and a little training, they could take in AIDS people. And if the State could help them out to the tune of $1,000 or $1,200 a month, whatever, they could gain a little income for themselves, be involved in something that is terribly constructive and useful to society, add a little income to their own lives, add a great deal of satisfaction to their own lives, and provide a very enriching and serene way of treating AIDS people in their final months or years, whatever it is.

I am not trying to put words into your mouth. I am giving you sort of two extremes.

Can you tell us in your experience, do you think what you have done can be widely replicated? Do you think there is enough of a germ of an idea here that we ought to set about writing some kind of a federally funded program to assist States and perhaps cities around the country to fund people like you and to provide the counseling, to provide the health outreach from a neighborhood hospital, perhaps, maybe not a tertiary hospital, maybe a community hospital or a nursing home, to provide enough outreach medical care to help folks like you across the country provide a hospice setting for AIDS people?

Mrs. JANE SMITH. First off, let me say, as I said before, this Project Home for AIDS is a pilot program, OK. Project Home for the mentally ill that has been going on in Baltimore for a few years has been widely accepted. There have been people that have opened their homes for this. I don't see why it can't carry over.

Mr. SCHEUER. You don't see anything intrinsic to the AIDS problem or AIDS people——

Mrs. JANE SMITH. Yes——

Mr. SCHEUER [continuing]. Or to the AIDS treatment that is required——

Mrs. JANE SMITH. It's definitely a different field. In hospice you do need training for. I don't see Project Home as being the answer. I see it as being a supplement to whatever the answer is. At this moment the numbers aren't high enough that Project Home would be overwhelmed.

Mr. SCHEUER. That's correct.

Mrs. JANE SMITH. But eventually they will be overwhelmed.

Mr. SCHEUER. But for the first 4 or 5 years, if the arithmetic that we have agreed on is any judge, climbing to, as I said, perhaps 100,000 or 125,000 in the fourth or fifth year and then a quarter of a million, still, in a country of 240 million, we ought to be able to handle a quarter of a million people, considering the number of elderly people who own their own homes who have lots of extra space, who have space on their hands and time on their hands and want to do something useful. It seems to me that it is possible that there is a germ of a real wonderful idea here that we ought to build on and extrapolate, extend, repeat, if it's replicable, if it's intrinsically replicable.

Mr. JOHN SMITH. I believe that hospice in the home is certainly able to be done. If we think a minute, each one of us has a family; and somebody in our family has died. Maybe they didn't die in the

home but they certainly probably got sick in the home. The important thing in regard to AIDS is education.

My personal belief is that it is a disease that is hard to catch. You have to work at it, mostly. Now, blood donors and this sort of thing may be another story.

Our problem in doing this is finding the resources. They are there, but being able to know where to get them. For instance, our patient right now needs dental work done. I know out there somewhere there is a dentist that is able to do that.

I would see legislation—I don't believe you can legislate family. But I do believe you can legislate to make it easier for families to do this.

Mr. SCHEUER. Let me ask you a couple of specific questions, because my time is limited.

Are these people ambulatory? Can they get about? Can they go out? Can they work part time?

Second question: How much health care do they need? Do they need it on a daily basis? Can they go to a hospital? Can they go to a nursing home for it and then come back?

Mr. JOHN SMITH. The person with us now is highly ambulatory. He is for all intents and purposes healthy at this point. He goes to Johns Hopkins—well, his next appointment is in 6 weeks. He was there yesterday. Ultimately though, he will become bedridden. Whatever opportunistic disease comes along, if he catches it, he will become very sick.

Our last patient was in and out of the hospital twice. His final remark was: I'm tired of it; I don't want to do it anymore. It's just too much.

Mr. SCHEUER. Are you capable of giving him, with some assistance perhaps, some neighborhood people who have had a few months or 6 months or so of training, are you capable of giving them the kind of home care, under hospital supervision, perhaps, that they need, taking them right straight through to the end if it's a terminal case?

Mrs. JANE SMITH. The last patient that we had that died, Jerry, was bedridden the whole time he was with us. Jerry needed to be bathed daily. Jerry's body functions failed him. So, he needed round-the-clock supervision and nursing care. Jerry came to live with us and died within a month's time.

I think you will find that, by the time that they are sick enough to be able to place in someone else's home, the paper work goes through and everything, we have not had any that has lived more than 4 months.

Mr. SCHEUER. So, it's not a question of several years; it's a question of several months.

Mrs. JANE SMITH. Right.

So, what you are looking at as far as by the time they actually go to someone else's home, there isn't much time left. They normally do need a great deal of nursing care. They start out ambulatory but end up in bed very fast.

Mr. SCHEUER. Is it high tech nursing care? Do you need a lot of tube[illegible]nd what not——

Mrs. JANE SMITH. No.

Mr. SCHEUER [continuing]. Or is it more personal care?

Mrs. JANE SMITH. It is more personal care. It is hygiene mostly. It is seeing to it that they take their medication. There is no tube feeding or suction or anything like that. So, you don't really have to——

Mr. SCHEUER. It doesn't have to be in a tertiary hospital setting.

Mrs. JANE SMITH. No.

Mr. SCHEUER. Do you—just one sentence because I am sure my time has run out. Do you think this program is susceptible of widespread replication?

Mr. JOHN SMITH. I certainly do.

Mr. SCHEUER. Let's say a quarter of a million or more.

Mr. JOHN SMITH. I certainly do. I don't see us as being unusual.

Mr. SCHEUER. Well, I see you as being mighty damned unusual.

Mr. JOHN SMITH. Well, all right. The only reason is that we were willing to do it first. We will take the risk.

Mr. SCHEUER. It reminds me of the old song of about 50 years ago: tell me pretty maiden, are there any more at home like you? Are there any more around like you? Are there a quarter of a million people like you in the country who can perform this marvelously compassionate caring service that you do?

Mr. JOHN SMITH. Well, there are already. They are doing it. They may all have the same last name, but they are doing it, with their own family.

Mr. SCHEUER. Thank you very much. I just can't express my admiration for the marvelous job you are doing.

Mr. JOHN SMITH. Thank you.

Mr. WAXMAN. Thank you, Mr. Scheuer.

Mr. Bates, do you have any questions?

Mr. BATES. No, Mr. Chairman.

Mr. WAXMAN. Mr. Sikorski, do you have any questions?

Mr. SIKORSKI. No.

Mr. WAXMAN. Thank you very much.

We very much appreciate your testimony today. I think this will be helpful to us as we look at the alternative care for AIDS patients other than being in the hospitals in those final days of their lives.

Thank you for being with us.

Our next witness is Dr. Drew Altman, vice president of the Robert Wood Johnson Foundation.

We are pleased to have you with us. Your prepared statement will be made part of the record in full. We would like to ask you, if you would, to summarize that statement in around 5 minutes.

STATEMENT OF DREW E. ALTMAN, PH.D., THE ROBERT WOOD JOHNSON FOUNDATION

Mr. ALTMAN. Thank you, Mr. Chairman.

The views expressed in my testimony are those of the author, and no official endorsement by the Robert Wood Johnson Foundation is intended or should be inferred.

Mr. Chairman and members of the committee, I appreciate the opportunity to make these remarks today. I want to commend you and your extraordinarily fine staff for being in the forefront of efforts to deal with this disease.

In my remarks today I want to summarize a major new AIDS program we recently announced and also discuss some of the problems we identified that led us to develop this program.

Let me say up front, though, that although we are proud that our program is the largest initiative to date, public or private, dealing with the services aspects of AIDS, I think we feel there is more bad news than good news in that fact, in that no private foundation can solve a major health care problem. The best we can do is help to demonstrate some new approaches and, even at that, we can be only partial funders in any large city. So, I think it is clear that there is a healthy agenda for further efforts here. At the end of my remarks I will make just one quick suggestion for Federal action that you might want to consider.

First of all, let me give you a thumbnail sketch of what we have done. This February we announced the AIDS health services program, which is a $17.2 million effort to improve health and supportive services for people with AIDS. Along with that, we made a variety of other grants including an effort to establish the first comprehensive pediatric AIDS center in New York, combined totalling some $20 million.

Let me give you a feeling for the key features of this program.

First of all, its thrust is to establish city-wide, highly specialized programs of AIDS health services that provide care from the hospital to the home, from the highly specialized inpatient unit and ambulatory clinic on the one end, to the kinds of hospice services and services in the home you heard about earlier today. The emphasis in the program is on out-of-hospital care, helping people with AIDS stay at home and remain in the community for as long as possible.

As you may know, it is a program which takes its inspiration from a very successful effort that is currently in place in San Francisco and makes available funds for others to adapt what San Francisco has done to their own circumstances.

Groups in the 21 metropolitan areas with the biggest problems are eligible to compete for funds. We will make 10 grants in October, of between $1.6 and $2 million each. Because one of our goals is to establish truly comprehensive programs, and because it is necessary in this to encourage Mayors and health departments and home health care agencies and big hospitals to work together who, as we all know, are often at each other's throats on such issues, we will make only one such grant in any big city.

Last on this list, as you know, and depending on Congressional action, the Public Health Service may have a $16 million program to support model projects in four cities. If in fact that program materializes, we anticipate working with them on a joint effort in those four cities. In fact, an agreement to that end has already been worked out with the PHS.

We developed our program to address some major problems in the delivery of services to people with AIDS. I want to highlight some of those for you. I must tell you, though, that when we first started to look at this, we assumed there was no role for our foundation in this area. Our assumption was that the health care system would be responding adequately to this problem. In the end, we broke our longstanding rule of never having supported any dis-

ease-specific efforts because of the problems we think we were able to identify.

First of all, as has been mentioned, things are going to get worse before they get better. Though the rate of new cases has slowed down a bit around the country, we still should expect a doubling to about 34,000 cases total in the next 12 to 24 months. As part of that, we will see more and more cities with significant problems. Today about 20 big cities have the same number of AIDS cases or more as did San Francisco just a few years ago.

Along with this, and I think not discussed often enough, we will see a doubling in the number of cases of ARC, or AIDS-related complex, which is the lesser forms of infection with the virus. Many but not all people with ARC require services. They all require monitoring. According to one estimate, about 10 percent are sufficiently debilitated that they require in-home care.

Researchers tell us that the number of cases of ARC may outnumber the number of cases of AIDS by about 10 to 1. Well, if that is true, we are facing about 300,000 cases of ARC in the next 10 to 24 months. Yet, I think we would all agree that the impact of that on our health care system is neither being widely discussed nor planned for.

There are some other aspects of this disease, too, which we are learning about which will have some impact—for example, the ability of the virus to move into the brain with Alzheimer's-like effects and the impact of that on the need for nursing home service. Also significant is the fact that some cities are going to be hit particularly hard by this disease, especially New York City and Newark, because of the I.V. drug use populations in those cities who are at high risk. They get AIDS by sharing contaminated needles and pass it on.

The rate of new cases has plateaued in San Francisco in part as the gay community has changed its behavior. I think New York City and Newark and Jersey City and some others can expect no such relief.

So, in short, we have concluded that this epidemic is going to worsen with the impact on the health care system increasing in parallel. It's an impact which is going to be felt particularly hard by a small number of big urban hospitals who care for the largest numbers of AIDS patients.

I think it is significant and not at all trivial that AIDS is now the number one diagnosis at Belleview hospital in New York City. I think that is the case at some other facilities as well.

Second, we concluded that in the main people with AIDS are not now getting the services they need and that the biggest failing is in the area we heard about today, in the area of out-of-hospital services. As a result, they wind up in the hospital sometimes when they don't need to be there, and they stay longer than is medically necessary. You can see that if you visit any of the hospitals heavily involved in AIDS care and talk to them about the backed up patients and talk with those patients. All of this is very expensive. The leading study on this estimates about $140,000 a case for hospital care alone.

Third, we concluded that specialized care was needed to deal with this disease properly. Regular care in the outpatient depart-

ment or inpatient floors doesn't work for AIDS. That is because you need teams of oncologists and infectious disease and pulmonary subspecialists to treat the cancers and infections and brain disease that afflict people with AIDS simultaneously, many times in combinations never before seen by physicians in this country. Specialized services are needed in other areas as well.

Fourth, and I think very importantly, we concluded that the emphasis in this area should be on out-of-hospital services. The care in the home and in the community is more compassionate, and in this instance it's much cheaper.

We all know that there is a big debate about whether these services save money by substituting for institutional care or cost money by reaching new populations. There really should be no such debate in this area and with this disease. That is because of the high probability, if not the certainty, that people with AIDS will be institutionalized and frequently if such services are not provided.

We saw in San Francisco, and I think it's of interest, real-world evidence that this is the case. The major studies of this, and now there are several, show that the hospital costs in San Francisco for AIDS average about $29,000 per case, versus an average of more than $140,000 across the country according to the same studies.

Even if that $111,000 difference is cut in half as other cities learn to deal a little better with this disease, it's still an extraordinary difference. In fact, even if you add the cost of the other services, the alternative services, to the hospital costs in San Francisco, San Francisco still weighs in a healthy 50 percent less expensive than the national average for hospital care alone.

Lastly, we hope our program will prove to be a significant one, but we also know that in the big picture a program like ours is a drop in the bucket. It is going to require broader efforts if we are to deal well with this disease.

What can the public sector do? Today I want to make just one very brief suggestion.

One step which I feel would be significant would be to establish an AIDS-only program waiver authority under Medicaid for States to develop in-home and community-based AIDS health services programs. Such programs—and I think this is important—could cover people with ARC where they met defined disability criteria. In contrast to the current waiver authority under Medicaid, which misses the mark for AIDS because it only operates as an alternative to nursing home care, and which is cumbersome, lengthy and uncertain, such waivers should be granted virtually automatically if accompanied by the appropriate documentation.

I think such a waiver program could also cover some services which are not allowed under the existing waiver, which are important if people with AIDS are to be maintained at home, for example, Meals on Wheels.

Finally, I think it might be well to consider a couple of other things as well through such a waiver authority. One would be enhanced reimbursements to big urban hospitals that establish specialized ambulatory clinics of the kind I described so that in fact they can maintain and treat AIDS patients on an ambulatory basis. Finally, perhaps also enhanced payments to nursing homes

who admit large number of AIDS patients so we can get them out of the hospital, and nursing homes will accept them.

In closing, let me just say that I think the private sector, too, has been slow to develop funding programs in this area. There is a healthy agenda for us in the private sector and the philanthropic world to consider as well.

I appreciate the opportunity to testify. I would be happy to answer any questions.

[The prepared statement of Mr. Altman follows:]

MORE EFFECTIVE AND LESS COSTLY AIDS HEALTH SERVICES

Drew E. Altman, Ph.D.
The Robert Wood Johnson Foundation
Princeton, New Jersey

Mr. Chairman, Members of the Subcommittee, my name is Drew Altman. I am Vice President of The Robert Wood Johnson Foundation. The Robert Wood Johnson Foundation, based in Princeton, New Jersey, is the country's largest private philanthropy in the health care field. Since we began our work as a national philanthropy in 1972, we have invested almost $700 million in research and demonstration efforts aimed at improving health and medical care for all Americans. In recent years, our emphasis has been on practical demonstration programs in three areas: improving access to health services for people having trouble getting them; finding safe ways to reduce health care costs; and helping the elderly, the chronically mentally ill and other vulnerable groups function independently in their daily lives.

In my statement today, I will describe the Foundation's new AIDS Health Services Program. I will also summarize the major conclusions that led us to develop the Program, tell you what we hope its accomplishments will be, and offer some suggestions for further public and private efforts dealing with AIDS.

On February 6, 1986, The Robert Wood Johnson Foundation announced the AIDS Health Services Program, a $17.2 million grants initiative to improve health and supportive services for people with AIDS and AIDS-related disorders. The key features of this Program are these:

- Its thrust is to establish citywide programs that will provide comprehensive, highly specialized AIDS services from the hospital to the home.
- The emphasis of the Program is on helping people with AIDS stay out of the hospital, remain at home, and function independently for as long as possible.

- The Program takes its inspiration from an effort already in place in San Francisco, which has demonstrated that services can be delivered to people with AIDS more compassionately and effectively and at substantially reduced cost.

- Groups in the 21 metropolitan areas with the largest AIDS case loads will be eligible to compete for funds, and we will make ten awards after a rigorous proposal review and site visit process. Awards will be made in October of 1986.

- 18 of the 21 cities will be eligible for grants of up to $1.6 million over four years, while the three cities with the largest AIDS case loads (New York, San Francisco, and Los Angeles) will be eligible for up to $2 million.

- In an effort to encourage citywide projects, and to encourage hospitals, health departments, home health agencies, voluntary organizations and others to work together to establish truly comprehensive programs, we will make only one grant in a metropolitan area. Each applicant will be required to establish a citywide advisory committee representative of the major groups dealing with AIDS in their area to provide broad oversight for their project.

- The Program will be administered for the Foundation by Mervyn Silverman, M.D., former Director of Health in San Francisco, and by a national advisory committee chaired by Philip Lee, M.D., Director of the Health Policy Institute, University of California, San Francisco, and President of the San Francisco Health Commission.

- Currently, the federal government is planning a grants program to support model AIDS health services projects in the four cities with the largest AIDS case loads. If the federal initiative goes forward, the Foundation and the federal government anticipate joining forces in a collaborative effort in these four cities, and an agreement to this end has already been worked out.

The citywide programs we will support will consist of:

- Comprehensive, AIDS-specific ambulatory services delivered by teams of subspecialists, which would result in improved diagnosis, earlier treatment and intervention, and reduced utilization of costly inpatient services. Such ambulatory clinics would also serve as a setting for needed clinical research on the treatment of AIDS.

- A range of home health and supportive services such as help provided by volunteers with cooking, shopping, dressing, and other basic tasks of daily living.

- Nursing facility and hospice services.

- o Case management services, usually provided by social workers or trained volunteers, to help patients and families navigate their way through the service and public benefits systems.

- o Innovative education and prevention activities aimed at members of potential high risk groups, such as i.v. drug users and others.

Ideally, these systems of care would be clearly linked to a specialized AIDS inpatient unit at a major hospital, as is the case in San Francisco, and a portion of Foundation funds could be used to establish such units.

To my knowledge, our Program is the largest initiative to date, public or private, dealing with the services aspects of AIDS. This is unfortunate, since no foundation program can hope to solve a major health care problem. Our resources are just too limited. Nor does our Program deal with all of the important aspects of AIDS health care. The best we can do is support efforts to help demonstrate new approaches and to replicate existing models that have been proven effective. Even at that, we can be only partial funders of a truly comprehensive effort in any big city.

We developed this Program to address several major problems and gaps in AIDS care and services. These problems will require further action by state and local government and the private sector if they are to be resolved. These are the major conclusions we drew as a result of our examination of this issue.

- o First, though science has made great progress in dealing with AIDS, neither a cure nor a definitive treatment is likely soon. As a result, though the rate of increase in new cases of AIDS has slowed in recent months, the number of new cases is still expected to double to approximately 34,000 in the next 12 to 24 months. As the numbers increase, many more big cities are facing significant AIDS problems. Approximately 20 cities have the same number or more cases of AIDS as did San Francisco just four years ago.

Along with this, we will see a doubling in the number of cases of AIDS-related complex or ARC, the lesser but still often serious forms of infection with the AIDS virus. Many but not all people with ARC require services, and all require monitoring. According to one estimate, as many as 10 percent are sufficiently debilitated that they require in-home services. Researchers suggest that the number of cases of ARC may outnumber the number of cases of full-blown CDC-defined AIDS by as much as 10 to 1. However, the burden on our health care system of as many as 300,000 cases of ARC in the next 24 months is neither being widely discussed nor planned for.

Similarly, we are now learning of the ability of the AIDS virus to invade the brain and central nervous system with serious and sometimes debilitating effects, whether or not the infected person develops other symptoms of the disease. Like Alzheimers disease, this will place new demands for long-term nursing care and patient management on our health care system.

Of special concern is the fact that AIDS is likely to hit New York City, Newark, Jersey City and other cities with large i.v. drug use populations particularly hard. I.V. drug users, whose practices are difficult to change through preventive programs, are at high risk for AIDS because they share contaminated needles. They then pass the virus on to their spouses, sexual partners, and unborn children. Approximately 50 percent of AIDS cases in these three cities are i.v. drug users. In San Francisco, where only a tiny percentage of AIDS cases are i.v. drug users, the rate of increase in new cases has now plateaued, in part because sexual behavior has changed in San Francisco's gay community. New York City, Newark, and Jersey City can expect no such relief.

In light of all these factors, we concluded that the AIDS epidemic is going to continue to worsen, with the burden on our health care system increasing apace.

- Second, we concluded that for the most part AIDS patients are not now getting the care and services they need, and the biggest failing is in the area of ambulatory, in-home, and other out-of-hospital services. As a result, many wind up in the hospital when they don't need to be there, or stay longer than is medically warranted for lack of services in the home or in the community that would allow them to be discharged. Hospitalization can be extraordinarily expensive. It has been estimated that the average cost of hospital care alone for AIDS patients is more than $140,000.

- Third, we concluded that specialized care is needed to properly treat people with AIDS. This is true in the hospital, where AIDS inpatient and outpatient units staffed by teams of oncologists, pulmonary and infectious disease subspecialists, and others are necessary to treat the cancers, infections, brain disease and other problems that often simultaneously afflict AIDS patients,

sometimes in combinations rarely or never before seen by physicians. It's equally true with regard to services in the home, where large AIDS volunteer programs are needed to help with cooking, cleaning, shopping, and providing emotional support. Specialization is also needed for prevention where, for example, new efforts to reach i.v. drug users must be developed if we are to slow the rate of new cases in this population.

- o Fourth, we concluded that the emphasis of these specialized AIDS service programs should be on out-of-hospital care. Nobody likes being in a hospital. Care in the home and in the community is more compassionate and in this instance it is much cheaper. Though the broader question of whether in-home and community-based services save money by substituting for institutional care or add costs by reaching new populations is being hotly debated, there can be little doubt that such services save money for people with AIDS. This is because there is such a high probability that they will be institutionalized repeatedly and for long stays if not cared for in the community.

  We saw in San Francisco real life evidence that this is the case. Recent studies have shown that hospital care in San Francisco averages $29,000 per AIDS patient, versus an average of more than $140,000 across the rest of the United States. Even if cut in half, this $111,000 difference per case would still be extraordinary. Political environments, AIDS populations, and health systems vary, but other cities can do what San Francisco has done, tailoring their approach to their own circumstances.

- o Finally, we concluded that the establishment of truly comprehensive specialized AIDS programs requires collaboration among a broad range of organizations, including health departments, big hospitals, home health agencies, voluntary organizations, and advocacy groups. Many of these may not have worked together in the past and may not agree on AIDS-related issues. Our experience has shown that a competitive grants program like this can encourage these groups to overcome these problems and join together around a concrete task for which outside funding is available.

We developed the AIDS Health Services Program to address these problems. But beyond the obvious goals of bringing services to people with AIDS and doing so more compassionately and at reduced cost, we hope it will have a broader impact in two areas.

First, AIDS has been called this nation's number one public health priority. I think that is appropriate, but the reason is not fundamentally in the number of new cases of the disease. Rather, it is because of the

public panic and hysteria that surrounds AIDS that it truly does represent an unprecedented national health care crisis. Furthermore, the fear of AIDS is not something from which the medical profession has been entirely immune. Even now, it is a disquieting experience to attend conferences on AIDS and find some medical professionals asking many of the same questions as the lay public. Using a health care program as a wedge, we hope to show that the country — and certainly our health care system — can face up to this disease and deal with it more rationally and effectively.

Second, San Francisco appears to have broken the golden rule of health care costs — that new services cost more. In this case (again, because of the high probability that people with AIDS would otherwise be institutionalized) these services save money. Caring properly for AIDS may teach us a great deal about how to handle other health care problems, and about when and how to expand our public programs to cover these services, even in an era of tight budgetary constraint.

In closing, let me return to an important theme. Namely, that though we hope our Program will prove to be a significant one, addressing the gaps and failures in the provision of services to people with AIDS will require broader action by both the public and private sectors.

The biggest obstacle to developing more effective, less costly health service arrangements for AIDS is financing, particularly for out-of-hospital services. Given today's budgetary environment, changes in Medicaid or Medicare to finance such services more broadly would appear to be infeasible. Similarly unlikely, I assume, is the suggestion being made by some to treat AIDS as we have treated end-stage renal disease since 1972, by providing Medicare or some other federal coverage for AIDS patients once

the disease is definitively diagnosed. Thus, it would seem that more limited steps should be considered.

One such step would be to establish an "AIDS only" program waiver authority under Medicaid for states to develop in-home and community-based AIDS service programs. Such programs could cover people with ARC as well as AIDS, where they met clearly defined disability criteria. In contrast to the current home and community-based waiver review process, AIDS program waivers would be granted automatically if requested by a state and accompanied by appropriate documentation. A special AIDS home and community-based waiver program could also cover some services not now covered under the existing waiver authority that are important in maintaining AIDS patients in noninstitutional settings, such as Meals-on-Wheels or limited subsidies for housing. Given the extraordinarily high hospital costs for AIDS patients ($140,000 per case according to the major study to date), a truly comprehensive package of noninstitutional services could be provided while still producing savings to the government and the taxpayer. An AIDS Medicaid waiver authority could also allow for enhanced ambulatory care payments to hospitals with significant concentrations of AIDS patients, and enhanced payments to nursing homes that admit people with AIDS. This would help the small number of hospitals now caring for a disproportionate share of AIDS patients to establish the highly intensive, specially staffed AIDS ambulatory clinics that are needed to treat AIDS patients on an outpatient basis, as is now being done at San Francisco General Hospital. Enhanced payments to nursing homes, in states that do not already have case-mix based nursing home payment, would encourage them to admit heavy-care AIDS

patients so they can be discharged from the hospital at the earliest possible opportunity.

Despite the ongoing debate about opening up public programs to such services, the fact is that doing so for AIDS makes sense from virtually all perspectives: it will save money; it is more compassionate; and it makes for better care.

Along with government, the private sector, and private philanthropy specifically, will also need to make a greater effort to support better approaches to care for people with AIDS. Private funding for AIDS programs has been slow to develop, and there is a healthy agenda for private funders to consider as well.

Mr. Chairman, thank you for the opportunity to present these remarks. You and your fine staff are to be commended for being in the forefront of efforts to grapple with this disease.

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Mr. WAXMAN. Thank you very much.

That was excellent testimony. We appreciate what you had to say.

The Robert Wood Johnson Foundation is funding some pilot projects, as you mentioned, to see what alternative care settings we might have for AIDS patients. We saw from the earlier witnesses what they are doing in Baltimore in a very limited way. You mentioned that the Department of Health and Human Services may be funding some pilot projects as well that you will be working with to look at various models. Is that correct?

Mr. ALTMAN. That is correct, if in fact the $16 million for the PHS program materializes.

Mr. WAXMAN. That $16 million was appropriated for that purpose?

Mr. ALTMAN. That's right. And I believe that the administration has proposed rescinding those funds. You will, I am sure, hear more about that later.

Mr. WAXMAN. We will be going to that in a short time with the administration witnesses.

What we really are talking about is with that $16 million, with the Robert Wood Johnson Foundation, with other models being set up, the whole health care system overall and people involved in it are looking for ways to handle these AIDS cases in a way other than institutionalization in a hospital, in a way that would be less costly and more humanitarian as well.

Now let me explore with you your suggestions specifically about what role Government might play. Most of these patients are not going to have their health care covered by Government funding. Is that correct?

Mr. ALTMAN. Most is correct, though a healthy percentage are covered by Medicaid, maybe 40 percent. It may be 25, depending on the part of the country.

Mr. WAXMAN. So, if Medicaid is paying for some of the services, anywhere from 25 to 40 percent of the services, it's in our interest, since the Federal Government is the prime funder of the Medicaid Program along with the State governments, to find an alternative care system that will save us money in fact. Is that a correct assumption? Is that the reason why we should be involved?

Mr. ALTMAN. Absolutely. And I think this is a case where it should be possible to punch through the impasse that has existed on some of these issues between liberals and conservatives and budget cutters and spenders, because there is just very little question that such services for AIDS will reduce expenditures overall. There are new studies on this that are not yet out, but their preliminary findings are showing that. The experience in San Francisco is showing that, too.

We are convinced of that, even though we believe that the literature on this issue broadly is equivocal.

Mr. WAXMAN. You mentioned the San Francisco model of providing a continuum of care for AIDS patients. Can you describe this model for us? Can you give us some of the data comparing costs between this model and other cities' experiences?

Mr. ALTMAN. First of all, I think the big question does have to do with costs. Specifically, doesn't it cost more when you add the costs

of these in-home and other services in San Francisco? And the answer is no. The answer is, even if you add those costs—and still the most expensive item in San Francisco is hospital care—even if you add those costs to the hospital costs in San Francisco, you are at well less than $50,000 per case, with a national average according to the study done at the CDC and published in the Journal of the American Medical Association, of $140,000 just for hospital care per case alone.

So, one could provide a truly comprehensive package of noninstitutional services and still save money in this area.

What does the system consist of? It has several characteristics. First of all, a full range of services, that is, from a dedicated inpatient unit at San Francisco General Hospital and a highly specialized ambulatory clinic with multidisciplinary team care, as I described, which is critical. It is a mistake to think that the only important services needed here are the in-home services. Dealing properly with this disease at the hospital is also critical.

San Francisco's full range of services goes beyond health and supportive services. It includes emergency residential facilities, which are hard to locate in communities but which they have been able to achieve there. And that's important because, if you visit a shelter for the homeless in New York City, sadly you will see significant numbers of AIDS patients there who have been moved out into the street for a variety of reasons and are essentially living out their final days.

In all, the city of San Francisco spends about $8 million a year on its AIDS programs, of which less than 2 million—I think it's probably closer to 1 million—goes to support these in-home and community based services. Some of the rest goes for institutional care for uncovered patients.

So, you are talking about in the city with the second highest number of AIDS cases a significant but still rather modest investment to cover these people who are falling through the cracks.

Mr. WAXMAN. When we look at the length of stay in hospitals, the average length of stay in a hospital in San Francisco is about 80 percent lower than in New York City for AIDS cases. Costs are also about 80-percent lower, although it's not clear from that 80-percent figure how much of the nonhospital costs are included in that figure. So, we are talking about nevertheless a substantial reduction in costs for the treatment of these patients from what we see in the San Francisco model, where they have a whole spectrum of care, from what we see comparing that to New York, where they have primarily, if not exclusively, hospital care.

Now, why do you recommend an AIDS-specific waiver for community services? Are there unique problems with AIDS care that a waiver would address?

Mr. ALTMAN. I recommend it for a couple of reasons, and there may be another route to Rome in terms of accomplishing the same thing. First of all, the existing waiver authority, home and community based waiver authority is intended only as an alternative to nursing home, not hospital care! Also, as I see it from Princeton, which is far away, it is cumbersome. There's a great debate about it. Waivers are hard to get. There's a big debate about whether

they save money or they don't. Even some States are nervous about how aggressive to be in this area.

So, I think it would make sense to have an expedited and dedicated or specific waiver authority for this disease, where again there's little question about saving money, and where the primary goal is to avoid hospital, not nursing home care.

Second, it would make sense to do some things for AIDS that are not done under the existing waiver authority, particularly covering some services, as I said, like Meals on Wheels and even conceivably some limited subsidies for housing. It also makes sense to add to that to deal with some of the other problems I mentioned. For example, it costs more than is reimbursed under already difficult circumstances on an outpatient basis by Medicaid around the country to establish these multidisciplinary ambulatory clinics, which is one of the linchpins of San Francisco General's program.

It would make sense to enhance payments so that institutions could establish such clinics and treat AIDS patients on an ambulatory basis.

For those reasons I think it might make sense, though, as I say, there may be other ways——

Mr. WAXMAN. We recommended in the reconciliation bill that is still pending hospice services under Medicaid. You are recommending a waiver under Medicaid for AIDS patients. Why not just use hospice care?

Mr. ALTMAN. Well, I think the range of services is much broader than can be provided through hospice care, though I think hospice services are an important part of the package. And I think that's the answer, because we're talking about more than hospice care. We are talking about transportation. We're talking about specialized ambulatory services at the hospital, and a variety of other things as well.

In addition, some further work may need to be done to apply a hospice benefit to the situation, which has its own unique characteristics in terms of frequency of serious episodes and costs and how you price that benefit, and so forth.

Mr. WAXMAN. If we provided for hospice benefit under Medicaid, if we also provided for a waiver under Medicaid, is it your opinion that we would be spending more dollars or fewer dollars that would otherwise be the case?

Mr. ALTMAN. In this instance I think, as I have said, you would be spending substantially fewer dollars. I think, even though this disease has come upon us quickly and the studies are small, I think that can be documented to everyone's satisfaction. I would be happy to submit the numbers on San Francisco for the record if they would be helpful.

Mr. WAXMAN. We would be pleased to receive it.

Thank you very much.

Mr.Whittaker.

Mr. WHITTAKER. I have no questions, Mr. Chairman.

Mr. WAXMAN. Mr. Scheuer.

Mr. SCHEUER. We heard from the young couple who operated their home AIDS hospice-like treatment that there was no health care involved in that. They had the patients around 4 or 5 months. Did I get a wrong impression with them, and they said there were

no tubes and no intravenous feeding, and so forth? Did I get a wrong impression from them that high tech health care in a tertiary hospital is really not part of the kind of treatment that is indicated for AIDS and that AIDS patients can be treated in a home with simply the kind of care that they described, as helping with their bodily functions, helping them bathe, and so forth, but not much high tech health care, which a hospital setting would be necessary?

Mr. ALTMAN. I think the answer may complicate your life, but I think the answer is it varies. For a good many AIDS patients, from what I have been able to observe, the situation described earlier applies. But certainly——

Mr. SCHEUER. Excuse me. Just elaborate.

Mr. ALTMAN. Low tech care, personal care.

But certainly high tech care, highly sophisticated team care is a critical part of the picture in terms of dealing with this disease and also dealing with it on an ambulatory basis. Consider a patient I saw in San Francisco who at one and the same time was suffering from serious neurological problems, cancer, two different life-threatening infections: phlebitis, which was moving from one leg to another. That patient was being maintained on an ambulatory basis. That is a set of conditions which physicians have seldom seen together before: how to treat it, what drugs to use, how do the drugs interact?

In San Francisco they have been flying by the seat of their pants on that, but now there is some knowledge about how to deal with this. This is more than just a personal care, low tech problem, though I think that is the highest priority.

Mr. SCHEUER. So, you think this home AIDS care that we heard about has a role and has a place in the total scheme of things but probably some rather sophisticated counseling and organization of the care is necessary?

Mr. ALTMAN. Absolutely.

Mr. SCHEUER. Now——

Mr. ALTMAN. And training.

Mr. SCHEUER. Yes.

In your research and demonstration models, let us say, for caring for AIDS patients, are we going to learn something about the ARC, the AIDS-related patients, that million or million and a half, about how to treat them and related cases? Are we going to learn something about acute and long-term care, patients other than AIDS, that is going to be an extremely valuable—that would be if it is produced—an extremely valuable fallout of the kind of demonstration projects you are talking about from it?

Mr. ALTMAN. The answer is yes. We think it's important to be accountable about what happens with our money. So, we will invest heavily, perhaps more than $1 million, in an independent evaluation of our projects, which will focus on three questions: did they save money or not; was the quality of life improved or not through these community programs; and, third, what can we learn about the dimensions of this disease? Though the CDC has decided to focus on CDC-defined full-blown AIDS, in the real world the problem in terms of the problem the health care system faces is

not that; it's a problem of a broad spectrum of infection with the AIDS virus, of which the most severe form is CDC-defined AIDS.

Mr. SCHEUER. But you will include the AIDS-related cases.

Mr. ALTMAN. And for that reason we will make that a priority in the evaluation.

Mr. SCHEUER. Yes, very interesting.

Thank you very much.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you.

Mr. Dannemeyer.

Mr. DANNEMEYER. I just wonder, Mr. Altman, could you describe the highly specialized services which your foundation envisions providing a little more distinctly than you described——

Mr. ALTMAN. The high tech——

Mr. DANNEMEYER [continuing]. High tech——

Mr. ALTMAN. The high tech end of the picture?

Mr. DANNEMEYER. Yes.

Mr. ALTMAN. Yes. They are in place in San Francisco and some other places now. They start with a dedicated AIDS inpatient unit, that is, a special unit in the hospital that deals with AIDS and is staffed by multidisciplinary teams of subspecialists who deal with the different problems people with AIDS have. You need oncologists to deal with the cancers. You need infectious disease physicians to deal with the life-threatening infections like pneumocystis pneumonia, which is the leading diagnosis.

You need neurologists to deal with the fact that we now know that this virus moves into the brain. In fact, some 80 percent of patients studied at Roosevelt St. Luke's in a study just completed in New York had serious or some neurological complications. You need specialized nurses. You need people who are not afraid, health professionals who are not afraid to deal with AIDS, which still remains a big problem with this disease.

So the first part on the high tech end is the AIDS inpatient unit. The second part, an ambulatory clinic that is staffed by the same people so that the treatments, whether that's antibiotics or other forms of treatment, which for people with full-blown AIDS buy time, and for people with ARC it could ultimately prove life saving, can be done on an outpatient basis.

The last piece of the high tech picture is, in addition to personal care in the home, high tech home health care. Antibiotics can be administered intravenously in the home, and that is done for a variety of conditions around the country now. And we need to develop a capacity through home health care agencies who do this work to do it for AIDS as well.

Mr. DANNEMEYER. How do these things you have just described differ from what is encountered in the hospital setting?

Mr. ALTMAN. AIDS patients typically now are scattered around the inpatient rooms in the hospital, or in an outpatient department, which is the general outpatient department. They show up, and they may even see whoever is there or be dealt with in the emergency room, be seen by a primary care physician who may or may not know enough about the specialized problems they have, by nurses and physicians who may or may not understand the psychological dimensions of this problem.

In San Francisco General, the volunteers who provide a lot of the personal care are also in the outpatient unit and in the inpatient unit. So, these people have these volunteers who are highly trained with them as part of the high-technology setting as well as the low-technology setting from the beginning. And that is an important part of that as well, a sort of melding of the two ends of the spectrum.

Mr. DANNEMEYER. Is it your claim that what you described can be provided at less cost than in a hospital setting?

Mr. ALTMAN. Absolutely.

I think even the high-technology services—the ambulatory clinics save money in the end because they allow you to treat patients on an ambulatory basis and not admit them. But even the inpatient units, which you would think of as costing more, may not cost more because of the economies of scale that are produced if you put all of that in one place rather than scattering it around the hospital and trying to deal with it on a business as usual basis. That doesn't work very well, leaving aside the fact that the care is much better when it is specialized.

You might think the people in San Francisco would feel stigmatized by this specialized system. Instead, they have overwhelmingly voted for it with their feet, vasting preferring care in the specialized units to other care in the community. And I think that is an important part of the picture, too.

Mr. DANNEMEYER. Thank you very much.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Dannemeyer.

Mr. Bates.

Mr. BATES. No questions, Mr. Chairman.

Mr. WAXMAN. Dr. Altman, we appreciate very much your testimony. We would like to have for the record any additional information on some of these figures that you might have so that we can make them available to the members of the subcommittee.

Thank you for being with us.

Mr. ALTMAN. Thank you again.

Mr. WAXMAN. Our next panel consists of Mr. John Kelso, Acting Administrator, Health Resources and Services Administration, who will be accompanied by Dr. Edward Martin, Acting Deputy Administrator, and Dr. Audrey Manley, Chief Medical Officer, Health and Human Services; as well as Mr. Elmer Smith, Director, Office of Eligibility Policy, Bureau of Eligibility, Reimbursement and Coverage, Health Care Financing Administration, accompanied by Mr. Robert Wren, Director, Office of Coverage Policy, Health Care Financing Administration.

I would like to welcome all of you to our hearing today. We are pleased to have you with us. Your prepared statements will be made part of the record in full. We would like to ask you to summarize those statements if you could, keeping as close to 5 minutes as possible.

Mr. Kelso.

STATEMENTS OF JOHN KELSO, ACTING ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY EDWARD MARTIN, ACTING DEPUTY ADMINISTRATOR; AND ELMER W. SMITH, DIRECTOR, OFFICE OF ELIGIBILITY POLICY, BUREAU OF ELIGIBILITY, REIMBURSEMENT AND COVERAGE, HEALTH CARE FINANCING ADMINISTRATION (HHS), ACCOMPANIED BY ROBERT WREN, DIRECTOR, OFFICE OF COVERAGE POLICY

Mr. KELSO. Thank you very much, Mr. Chairman.

On my left is Dr. Manley, who is the coordinator of AIDS activities in the agency. On my right is Dr. Martin, who is the Acting Deputy Administrator.

As you well know, the AIDS problem has been a No. 1 priority activity for the Public Health Service. Primarily PHS activities have been related to research, vaccine development, safety of the blood supply (FDA), prevention, epidemiology and surveillance (CDC), and some of the psychosocial aspects (ADAMHA).

Within the Health Resources and Services Administration, Dr. Manley is our representative on the PHS Executive Task Force on AIDS. She also chairs a work group of the task force on patient care and service delivery.

Our activities have been pretty much limited to disseminating information on AIDS to the beneficiaries for whom we provide care within the agency, namely community health centers, State and local activities, and the Indian Health Service.

I would be glad to entertain any questions.

[Mr. Kelso's prepared statement follows:]

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STATEMENT

BY

JOHN H. KELSO

ACTING ADMINISTRATOR

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Mr. Chairman and Members of the Subcommittee:

I am John Kelso, Acting Administrator of the Health Resources and Services Administration. Accompanying me this morning are Dr. Edward Martin, Acting Deputy Administrator and Dr. Audrey Manley, Chief Medical Officer of our Agency. She is also Chairperson of the PHS AIDS Executive Task Force's Work Group on Patient Care and Health Services Delivery.

Background on AIDS

Acquired Immune Deficiency Syndrome (AIDS) is a viral disease which causes a complex of health conditions by creating a basic defect in a person's immune system and by direct action of the virus on the person's central nervous system. A person with AIDS is vulnerable to infections and often develops a number of opportunistic diseases. According to the Centers for Disease Control (CDC), AIDS cases continue to increase, making it a public health problem unprecedented in recent history. For example, the number of cases of AIDS doubled between February 1985 and January 1986. The total number of cases reported as of February 24, 1986, was 17,741. Not one of these patients has recovered lost immunity, and over half (9,294) have died. The mortality rate is high; those diagnosed for two years or longer have a mortality rate of over 75 percent.

Epidemiological studies by CDC suggest that approximately one million persons in the United States are infected with the AIDS virus. It is estimated that 5 to 10 percent of these persons will develop AIDS within 5 years after becoming infected with the virus. About 25 percent will go on to develop AIDS related complex (ARC), a milder form of the disease. An infected person carries the virus for life, is capable of transmitting the virus to others, and remains at risk for developing the disease for at least 7 years. The disease is still largely confined to two groups in the United States: homosexual or bisexual men (74 percent) and I.V. drug users (17 percent).

Epidemiological studies by CDC and the National Institutes of Health (NIH) have defined the following routes of transmission of HTLV III: sexual contact from infected men to male and female partners and from infected women to male partners; exposure to infected blood through sharing of needles among I.V. drug users, blood transfusions or use of other blood products; and perinatally, from infected mother to infant.

To date the AIDS virus has been isolated from blood, semen, saliva, tears, and urine. It is likely to be isolated from other body fluids, secretions, and excretions. However, epidemiologic evidence has implicated blood and sexual contact as the major modes of transmission.

Epidemiological studies of household contacts of AIDS patients and of health care workers caring for AIDS workers indicate that AIDS is not spread by casual contact, such as sneezing, coughing, or sharing of meals.

The PHS Response

Since 1981, when the first case of what was later termed AIDS was reported to CDC, it has been and continues to be the number one priority of the Public Health Service (PHS). Considerable progress has been made by the PHS in combating this devastating disease.

Shortly after the first cases were reported, a PHS coordinating group was established by the Assistant Secretary for Health to bring the scientific resources of all PHS agencies to bear on the problem. That group, reformulated and now called the PHS Executive Task Force on AIDS, meets biweekly and is an important forum to communicate, coordinate, review policy and formulate future plans for combating this disease. It is currently chaired by the PHS AIDS Coordinator, Dr. Walter Dowdle.

As a PHS agency, the Health Resources and Services Administration (HRSA) is a member of the PHS Executive Task Force on AIDS. We chair its work group on Patient Care and Health Services Delivery, created in November 1985, at the direction of the former Acting Assistant Secretary for Health, Dr. James Mason.

The work group has membership from CDC; the Food and Drug Administration (FDA); NIH; the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA); the Office of the Assistant Secretary for Health; the Health Care Financing Administration (HCFA); and the Regional Offices.

The PHS has worked with many public and private organizations to develop guidelines to assist State and local officials to make decisions on how best to protect the public health. These guidelines, published by CDC, are based on the best available scientific evidence and are updated as new data become available. For example, in 1983 blood donation guidelines for members of groups at increased risk for AIDS were issued. In August 1985, PHS issued guidelines for schools, after school day care, and children placed in a foster home, that recommended most AIDS infected children should be allowed to attend school. In November 1985, PHS issued guidelines for the prevention of AIDS in the workplace with emphasis on health care, food service, and personal service workers. The guidelines indicate that the kind of nonsexual person-to-person contact that occurs among workers and clients or consumers in the workplace does not pose a risk for transmission of AIDS. In December 1985, PHS issued guidelines on the prevention of perinatal transmission of the AIDS virus.

The PHS is working to control and prevent AIDS by the year 2000. We published our plan for achieving this goal in the September October 1985 issue of Public Health Reports. The plan is based on the state of the art since the isolation of the AIDS virus and development of the blood test to detect evidence of infection by the virus.

PHS activities include a broad-scale information and education program in addition o research efforts to develop a vaccine, and treatments to fight the AIDS virus and restor functioning of the immune system.

The information and education program applies our current knowledge on transmission to substantially curtail the spread of the disease. PHS has developed a pamphlet, Facts about AIDS, that is being widely distributed to all Americans. We have printed over 1 million copies and are distributing them in various ways, for example: in response to individual requests; through health clinics; and in supermarket information racks across the country.

AIDS and Health Care Delivery

The PHS has not been involved in direct provision of health care for AIDS patients beyond those identified beneficiary populations for which the PHS has responsibility (e.g., American Indians, Alaska Natives, etc.). Health care services for others with AIDS has been the responsibility of the various State and local governments, and private sector organizations.

However, the PHS, through the Health Resources and Services Administration, supports primary care health services provided in Community Health Centers (CHCs), Migrant Health Centers (MHCs), and Maternal and Child Health (MCH) service clinics and projects. A number of such programs are located in high risk geographical areas of the country such as New York City, San Francisco and Miami.

An important HRSA activity to date has been the dissemination of education and information materials about AIDS to health care providers in PHS programs, service sites, and health professional training programs. Information and education materials on AIDS are disseminated to State MCH Directors, Hemophilia Centers, State MCH Social Work Consultants, State MCH Nurse Consultants, State and Territorial Dental Directors, CHCs, MHCs, National Health Service Corps (NHSC) practitioners, Indian Health Service (IHS) field sites and Regional Office service delivery programs staff.

There is a wide range between estimates of the cost of caring for patients with AIDS. The costs depend on a variety of factors including which opportunistic disease(s) the patient gets, the patient's geographic location, and the availability of alternative health care outside the hospital.

Varied approaches to inpatient care are occurring at the local level. These include special ambulatory clinics, home health care, semi-residential facilities, nursing home care and special support services. For example, San Francisco has developed a comprehensive, community-based program for AIDS patients that includes: 1) a highly specialized AIDS clinic based at San Francisco General Hospital (SFGH); 2) home health care services; 3) a community-based counseling and supportive service program; 4) skilled nursing facilities; 5) hospice care; 6) an education and prevention program; 7) transportation services; and 8) emergency residential facilities for AIDS patients who can no longer afford housing. New York is in the process of formulating a program model for AIDS patient services that includes home health care, hospice care and psychosocial and psychiatric service components.

The Robert Wood Johnson Foundation has announced that it will initiate a $17.2 million grant program to support the establishment of specialized comprehensive health and supportive services programs for people with AIDS and ARC. Up to 10 grants

will be made under the program in the 21 Metropolitan Statistical Areas with the largest concentration of AIDS patients. A national advisory committee will be developed to assist in the review of applications, monitoring of the ongoing operation of the program and to provide technical assistance to the program and the selected applicants. The committee will include PHS representation.

The HRSA continuously disseminates information on AIDS to the health care providers and the beneficiary populations of HRSA programs. This is done through conferences, workshops, and printed and audio visual materials.

This concludes my statement, Mr. Chairman. We would be happy to answer any questions you or other members of the Subcommittee may have.

Mr. WAXMAN. Mr. Smith.

STATEMENT OF ELMER W. SMITH

Mr. ELMER SMITH. Mr. Chairman and members of the committee, I am here today in my capacity as HCFA's coordinator of AIDS-related issues. I am the HCFA representative on the PHS Executive Task Force on AIDS. I am also the HCFA representative on the PHS work group on patient care and service delivery for persons with AIDS.

Mr. Wren, who is with me today, heads our Office of Coverage Policy, which establishes national policy on coverage of Medicaid and Medicare services. He and his staff are also responsible for making recommendations about home and community based service waivers.

Now, the Medicaid Program serves about 40 percent of AIDS patients at any one time. It is estimated that about 50 million dollars' worth of Federal funds and $50 million of State funds were spent on behalf of AIDS patients in fiscal year 1985. In fiscal year 1986 about 100 million dollars' worth of Federal funds and a similar amount of State funds will be spent by the States under the Medicaid Program.

The Medicaid Program provides in every State a relatively broad range of services that are available to everyone who is eligible under the program. Consequently, that includes persons who have AIDS. These services involve both institutional services and community-based care. For example, in the mandatory services, which are required to be provided to all cash assistance recipients, and in most States to medically needy persons, there are inpatient and outpatient hospital services, physician services, laboratory and x-ray services, skilled nursing facility [SNF] services, home health services for persons over age 21 who are eligible for SNF care, and early screening, diagnosis, and treatment services for individuals under 21.

In addition, many States provide a variety of optional services. Many of the States that have the highest incidence of AIDS provide the broadest range of optional services. These can include clinic services, prescribed drugs, skilled nursing home services, and home health services for persons under age 21, miscellaneous diagnostic services, and personal care services.

There has been talk about waivers this morning. I want to talk about two groups of waivers which already exist under the Medicaid Program.

First, under the home and community-based service waivers, which are focused specifically on providing care to persons in the community who otherwise would have to be institutionalized, packages can be developed and can include services for AIDS patients. In addition, under the home and community-based service waiver authority, it is possible to provide some services that are not otherwise available under a State's regular ongoing Medicaid Program. So, if a State wants to design a package and include such things as habilitative services or hospice services under the home and community-based service waivers, they can do so.

In addition, case management is provided under home and community-based service waivers.

Furthermore, under the so-called freedom of choice waivers which are available under the Medicaid Program, AIDS patients can be afforded case management services and, where it is appropriate, can be restricted to receiving their services from certain types of providers who are cost effective and efficient.

So, these are two very important waiver authorities now in existence.

Mr. Chairman, that concludes my statement. I would be happy to try and answer any questions.

[The prepared statement of Mr. Smith follows:]

STATEMENT OF

ELMER W. SMITH

DIRECTOR, OFFICE OF ELIGIBILITY POLICY
BUREAU OF ELIGIBILITY, REIMBURSEMENT AND COVERAGE
HEALTH CARE FINANCING ADMINISTRATION

MR. CHAIRMAN, I AM ELMER SMITH, DIRECTOR OF THE OFFICE OF ELIGIBILITY POLICY, BUREAU OF ELIGIBILITY, REIMBURSEMENT AND COVERAGE. I AM ALSO THE COORDINATOR FOR HEALTH CARE FINANCING ADMINISTRATION (HCFA)-RELATED ISSUES CONCERNING ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) AND HCFA'S REPRESENTATIVE TO THE PUBLIC HEALTH SERVICE'S TASK FORCE ON AIDS. I AM ACCOMPANIED BY ROBERT WRENN, DIRECTOR OF THE OFFICE OF COVERAGE POLICY. MY COMMENTS TODAY WILL FOCUS ON THE SERVICES WHICH ARE AVAILABLE TO AIDS PATIENTS WHO BECOME ELIGIBLE FOR THE MEDICAID PROGRAM, THE DELIVERY OF SERVICES THROUGH SEVERAL TYPES OF MEDICAID WAIVERS, AND ESTIMATES BY HCFA ON THE COSTS BORNE BY THE PROGRAM TO PROVIDE HEALTH CARE SERVICES TO AIDS VICTIMS.

THERE ARE NOW ALMOST 18,000 PERSONS WHO HAVE BEEN REPORTED TO THE CENTERS FOR DISEASE CONTROL (CDC) AS DIAGNOSED WITH AIDS WITH OVER HALF OF THE VICTIMS HAVING DIED FROM CLINICAL MANIFESTATIONS OF THE SYNDROME. THE MEDICAID PROGRAM HAS CONTRIBUTED TO THE SUPPORT OF PATIENT CARE FOR SOME PERSONS WITH AIDS. WE ESTIMATE THAT 40 PERCENT OF AIDS PATIENTS ARE BEING SERVED UNDER MEDICAID AT ANY GIVEN TIME; IN CONTRAST, WE ESTIMATE THAT ONLY ONE PERCENT ARE RECEIVING CARE UNDER THE MEDICARE PROGRAM.

MOST AIDS VICTIMS QUALIFY FOR MEDICAID BY BECOMING DISABLED. AFTER DISABILITY IS ESTABLISHED BY MEETING THE CDC'S DEFINITION OF AIDS, CERTAIN INCOME AND RESOURCE CRITERIA MUST

BE MET BEFORE BOTH SUPPLEMENTAL SECURITY INCOME (SSI) CASH BENEFITS AND MEDICAID BENEFITS ARE PROVIDED. IN THE EARLY STAGES OF AIDS, ADULT PERSONS AFFLICTED WITH THE ILLNESS GENERALLY HAVE SOME RESOURCES, INCOME, OR HEALTH INSURANCE COVERAGE. HOWEVER, INCOME AND RESOURCES ARE OFTEN LOST OR REDUCED AS THE DISEASE PROGRESSES AND AIDS VICTIMS CAN BECOME ELIGIBLE FOR SSI PAYMENTS. EVEN IF PERSONS WITH AIDS DO NOT QUALIFY FOR CASH ASSISTANCE BENEFITS UNDER SSI, THEY FREQUENTLY CAN BECOME ELIGIBLE FOR MEDICAID AS MEDICALLY NEEDY INDIVIDUALS THROUGH THE "SPEND DOWN" PROCESS WHEN THEY INCUR EXTENSIVE BILLS FOR HEALTH CARE. AIDS PATIENTS CAN QUALIFY AS MEDICALLY NEEDY UNDER MEDICAID IN THE 30 STATES WITH THESE PROGRAMS.

IN ADDITION TO THIS SSI POPULATION, WE BELIEVE THAT THERE ARE SOME AIDS PATIENTS WHO WERE MEDICAID ELIGIBLE PRIOR TO DEVELOPING AIDS SUCH AS PERSONS RECEIVING CASH BENEFITS UNDER THE AID TO FAMILIES WITH DEPENDENT CHILDREN PROGRAM.

SERVICES

THE SCOPE OF COVERED SERVICES UNDER MEDICAID VARIES CONSIDERABLY FROM STATE TO STATE. ALL STATES MUST COVER CERTAIN MANDATORY SERVICES FOR SSI CASH RECIPIENTS AND, FOR ALL PRACTICAL PURPOSES, FOR THE MEDICALLY NEEDY. MANDATORY SERVICES WHICH WOULD MOST LIKELY BE UTILIZED BY AIDS PATIENTS ARE INPATIENT HOSPITAL SERVICES, OUTPATIENT HOSPITAL SERVICES,

RURAL HEALTH CLINIC SERVICES, OTHER LABORATORY AND RADIOLOGY SERVICES, SKILLED NURSING FACILITY SERVICES, AND HOME HEALTH CARE FOR INDIVIDUALS AGED 21 AND OVER.

STATES MAY ALSO CHOOSE TO COVER ADDITIONAL SERVICES AS SPECIFIED IN FEDERAL REGULATIONS. SOME EXAMPLES OF OPTIONAL SERVICES OFFERED INCLUDE CLINIC SERVICES, PRESCRIBED DRUGS, INTERMEDIATE CARE FACILITY SERVICES, MISCELLANEOUS DIAGNOSTIC SERVICES, SKILLED NURSING FACILITY AND HOME HEALTH SERVICES FOR INDIVIDUALS UNDER 21 YEARS OF AGE, AND OTHER ANCILLARY SERVICES SUCH AS PERSONAL CARE SERVICES, PRIVATE DUTY NURSING, PRIVATE PRACTITIONERS' SERVICES, AND REHABILITATION SERVICES. NEARLY HALF THE STATES OFFER 20 OR MORE ADDITIONAL SERVICES. CALIFORNIA AND NEW YORK, WHICH HAVE RECORDED APPROXIMATELY 67 PERCENT OF ALL REPORTED AIDS CASES IN THE UNITED STATES, PROVIDE 31 AND 24 OPTIONAL SERVICES, RESPECTIVELY, TO THEIR MEDICAID POPULATIONS.

TO MEET THE SPECIAL NEEDS OF MEDICAID-ELIGIBLE AIDS PATIENTS, STATES MAY OFFER A WIDE VARIETY OF SERVICES THAT CAN BE USED IN CONJUNCTION WITH EACH OTHER TO PROVIDE A SURROGATE FOR SERVICES WHICH MIGHT NOT OTHERWISE BE AVAILABLE. FOR EXAMPLE, HOSPICE SERVICES ARE NOT A DEFINED MEDICAID SERVICE THAT CAN RECEIVE FEDERAL REIMBURSEMENT, BUT STATES CAN DEVELOP A CLUSTER OF SERVICES SUCH AS CLINIC SERVICES,

PHYSICIAN VISITS, HOME HEALTH SERVICES, AND PERSONAL CARE SERVICES THAT REPRESENT A HOSPICE-LIKE PACKAGE OF SERVICES.

ALTERNATIVE DELIVERY SYSTEMS

STATES HAVE THE ABILITY TO IMPLEMENT INNOVATIVE HEALTH CARE DELIVERY AND MANAGEMENT ALTERNATIVES UNDER MEDICAID THROUGH TWO TYPES OF PROGRAM WAIVERS WHICH ARE SUBJECT TO A DEPARTMENT REVIEW AND APPROVAL PROCESS.

A STATE MAY APPLY FOR A HOME AND COMMUNITY-BASED SERVICES WAIVER WHICH ALLOWS IT TO TARGET COST-EFFECTIVE, COMMUNITY-BASED SERVICES TO MEDICAID ELIGIBLES WHO ARE AT RISK OF BEING INSTITUTIONALIZED WITHOUT SUCH SERVICES. AIDS PATIENTS COULD BE INCLUDED ALONG WITH OTHER PERSONS IN SUCH A WAIVER PROGRAM TO PROVIDE A BROAD RANGE OF SERVICES IN THE COMMUNITY RATHER THAN BEING SERVED IN COSTLY LONG-TERM CARE FACILITIES. ALTERNATIVELY, STATES MAY DEVELOP "MODEL WAIVERS" WHICH CAN BE EXCLUSIVELY TARGETED TO CERTAIN GROUPS OF MEDICAID-ELIGIBLES SUCH AS AIDS PATIENTS.

SINCE INFORMATION ON HOME AND COMMUNITY-BASED SERVICES WAIVERS IS NOT COLLECTED ON THE ILLNESS OR DISABILITY OF SPECIFIC CLIENTS, WE DO NOT KNOW IF ANY PATIENTS WITH AIDS WHO ARE MEDICAID ELIGIBLE ARE CURRENTLY RECEIVING SERVICES UNDER EXISTING WAIVERS AND THERE HAVE BEEN NO STATE WAIVER APPLICATIONS WHICH HAVE SPECIFIED ELIGIBLE AIDS PATIENTS IN THE TARGET POPULATION.

STATES MAY ALSO APPLY FOR A MEDICAID FREEDOM OF CHOICE WAIVER WHICH ENABLES THEM TO IMPLEMENT A NUMBER OF CREATIVE OPTIONS FOR DELIVERY AND MANAGEMENT OF HEALTH CARE SERVICES. ONE TYPE OF WAIVER PERMITS A STATE TO PLACE GROUPS OF RECIPIENTS UNDER A CASE-MANAGEMENT SYSTEM WHERE A PHYSICIAN OVERSEES A PATIENT'S TOTAL HEALTH CARE NEEDS. CASE MANAGEMENT MIGHT BE ESPECIALLY USEFUL FOR STATES TO MANAGE THE CARE FOR AIDS PATIENTS WHILE ASSURING THAT THE MOST COST-EFFECTIVE, HIGH QUALITY CARE IS PROVIDED.

LIKE HOME AND COMMUNITY-BASED SERVICE WAIVERS, FREEDOM OF CHOICE WAIVERS' INFORMATION IS NOT COLLECTED ON THE ILLNESS OR DISABILITY OF SPECIFIC CLIENTS SO WE DO NOT KNOW HOW MANY AIDS PATIENTS MAY BE COVERED UNDER ANY EXISTING WAIVERS. TO OBTAIN DEPARTMENT APPROVAL FOR EITHER TYPE OF WAIVER, STATES MUST DOCUMENT THE COST EFFECTIVENESS OF THE PROJECT; DESCRIBE THE EFFECT OF THE PROJECT ON RECIPIENTS; AND DESCRIBE WHAT THE PROJECT HOPES TO ACHIEVE AND HOW THAT IS CONSISTENT WITH THE OBJECTIVES OF THE MEDICAID PROGRAM. THERE ARE OTHER STATUTORILY REQUIRED CONDITIONS AND DOCUMENTATION REQUIREMENTS UNIQUE TO EACH OF THE WAIVERS WHICH MUST ALSO BE MET.

WE ARE AWARE THAT MANY STATES ARE EXPERIMENTING WITH ALTERNATIVE FORMS OF PROVIDING CARE TO AIDS PATIENTS THAT WOULD EMPHASIZE LESS USE OF INPATIENT HOSPITALIZATION AND MORE OUT OF

HOSPITAL COMMUNITY HEALTH AND SOCIAL SERVICES. THE ROBERT WOOD JOHNSON FOUNDATION ANNOUNCED IN EARLY FEBRUARY THAT IT WAS INVITING PROPOSALS FROM ABOUT 20 CITIES WITH LARGE NUMBERS OF AIDS CASES WHICH WOULD FOCUS ON REDUCING THE COST OF CARE WHILE PROVIDING A BROAD RANGE OF MEDICAL AND SOCIAL SERVICES TO AIDS PATIENTS. THE $17.2 MILLION IN GRANTS SHOULD BE AWARDED LATER THIS YEAR.

Costs

COST DATA FOR THE MEDICAID PROGRAM ARE BASED ON LIMITED AND FREQUENTLY ANECDOTAL INFORMATION BECAUSE OF OUR CURRENT INABLILITY TO COLLECT DATA ON THE BASIS OF DIAGNOSIS. GIVEN THE AGGREGATE STATISTICAL DATA THAT IS CURRENTLY AVAILABLE FOR MEDICAID, IT IS NOT POSSIBLE TO SEPARATE OUT AIDS PATIENTS AND THEIR EXPENDITURES. THE BEST WAY TO PRODUCE ACCURATE STATISTICS FOR AIDS PATIENTS IS TO DIRECTLY IDENTIFY PERSONS WHO HAVE AIDS IN PERSON-LEVEL DATA SETS. SINCE CONFIDENTIALITY IS A PRIME ISSUE WITH RESPECT TO THE IDENTITY OF AIDS PATIENTS, THERE MAY BE LIMITS ON THE AVAILABILITY OF THESE DATA.

HCFA HAS AN ONGOING RESEACH EFFORT CALLED THE MEDICAID TAPE-TO-TAPE PROJECT THAT USES PERSON-LEVEL DATA ON PROGRAM ENROLLEES,SERVICES, EXPENDITURES, AND PROVIDERS IN FIVE STATES (INCLUDING CALIFORNIA AND NEW YORK). HCFA HAS

SIGNED AN INTERAGENCY AGREEMENT WITH THE PUBLIC HEALTH SERVICE TO DEVELOP STATISTICS ON SEXUALLY TRANSMITTED DISEASES (INCLUDING AIDS) AND OTHER SELECTED DIAGNOSIS CATEGORIES FOR MEDICAID ENROLLEES. WHILE THE TAPE-TO-TAPE DATA ARE PERSON-BASED, IT IS NOT POSSIBLE TO DIRECTLY DETERMINE WHICH ENROLLEES HAVE AIDS. WE WILL CONTINUE TO STUDY THE POSSIBILITY OF OBTAINING AIDS COST INFORMATION FROM THIS DATA SOURCE.

BECAUSE OF THESE DATA PROBLEMS, HCFA HAS HAD TO GATHER INFORMATION FROM PUBLIC AND PRIVATE SOURCES IN ORDER TO ESTIMATE THE FEDERAL MEDICAID COSTS OF PROVIDING HEALTH CARE TO AIDS PATIENTS. AFTER EXTENSIVE REVIEW OF THIS LIMITED DATA, OUR BEST ESTIMATE IS THAT $50 MILLION IN FEDERAL MEDICAID FUNDS WAS EXPENDED DURING FISCAL YEAR 1985 FOR CARE TO AIDS VICTIMS, AND IN FISCAL YEAR 1986, $100 MILLION WILL BE SPENT. WE WILL BE MAKING ANY NECESSARY ADJUSTMENTS TO THAT ESTIMATE AND PROJECTIONS FOR FISCAL YEAR 1987 IN SEVERAL MONTHS WHEN WE HAVE MORE RECENT COST DATA.

<u>SUMMARY</u>

MEDICAID IS CURRENTLY PROVIDING NECESSARY SERVICES TO APPROXIMATELY 40 PERCENT OF AIDS SUFFERERS WHO HAVE NO OTHER SOURCES OF PAYMENT AND MEET ELIGIBLITY REQUIREMENTS OF THE PROGRAM. FOR THOSE AIDS PATIENTS, STATES CAN EXERCISE

CURRENT MEDICAID PROGRAM FLEXIBILITY IN ADOPTING INNOVATIVE DELIVERY SYSTEMS TO PROVIDE HIGH QUALITY CARE IN THE MOST COST-EFFECTIVE SETTING. THIS WILL ENABLE MEDICAID-ELIGIBLE AIDS SUFFERERS TO RECEIVE CARE IN A WIDE RANGE OF SETTINGS AND HOPEFULLY ALLEVIATE AS MUCH SUFFERING AS POSSIBLE DURING THE COURSE OF THE DISEASE.

HCFA WILL CONTINUE TO MONITOR THE EFFECTS ON MEDICAID OF CARE PROVIDED TO AIDS PATIENTS BY SEEKING CURRENT AND RELEVANT INFORMATION FROM ALL AVAILABLE SOURCES. THIS WILL ENABLE US TO BETTER ESTIMATE THE COST IMPACT TO THE MEDICAID PROGRAM OF PROVIDING CARE TO MEDICAID-ELIGIBLE PERSONS WITH AIDS.

THANK YOU FOR THE OPPORTUNITY TO APPEAR BEFORE THE SUBCOMMITTEE TODAY. I WILL BE HAPPY TO ANSWER ANY QUESTIONS YOU MAY HAVE.

Mr. WAXMAN. Thank you very much.

Let me start with Mr. Kelso. Let me begin with a question about your testimony. You say that the cost of AIDS care varies widely and that the costs depend on a variety of factors, including the availability of alternative health care outside the hospital.

Do you now have any services projects to promote what you call alternative health care outside the hospital?

Mr. KELSO. Not in HRSA, no, sir.

Mr. WAXMAN. The Labor HHS appropriations bill for this year contains $16 million for demonstration projects on the delivery of health services to people with AIDS. I know that it is part of the administration's proposal to cut 21 percent from AIDS funding this year. The administration has proposed to rescind that demonstration project money.

I do, however, have some questions about these appropriated funds. Before OMB came in and said it intends to request the Congress rescind the money, did you at the Health Resources Services Administration have any plans for how to develop models for AIDS care?

Mr. KELSO. Yes, sir; when the appropriation was passed and the money was technically in the Office of the Secretary's account, we convened a group. We developed some plans. We met with the Robert Wood Johnson Foundation people to talk about their activities. We submitted a plan to the Assistant Secretary for Health, which outlined our thoughts as to where we would be going.

When the rescission was proposed, we ceased work on the activity.

Mr. WAXMAN. You started to work on the plan?

Mr. KELSO. Yes, sir.

Mr. WAXMAN. We would like to have you submit to us what you have worked out as of this date.

Mr. KELSO. I would be glad to.

Mr. WAXMAN. We would like to have that for the record.

[Testimony resumes on p. 68.]

[The following information was submitted for the record:]

HRSA Proposal for Development of Service Delivery Demonstration Models for AIDS

The Acquired Immune Deficiency Syndrome (AIDS) is the current top priority issue of the Public Health Service. PHS is working through its basic scientific research, surveillance and regulatory agencies to determine the incidence of AIDS, its origin, its natural course and to develop reliable diagnostic, treatment and prevention procedures.

The Senate FY 1986 Appropriation Bill includes $16 million to develop... "four projects demonstrating the delivery of health care services to victims of acquired immune deficiency syndrome."

HRSA has developed the following proposal and approach for the development of such a service delivery demonstration in the event that this congressional directive becomes law. This initial proposal is subject to revision based on further guidance from the PHS Executive Committee on AIDS and from other PHS agencies.

BACKGROUND:

AIDS is a disease believed to be caused by the retrovirus HTLV-III (human T-cell lymphotropic virus, type III) and characterized by a deficiency of the immune system. The first case of AIDS was reported to the Centers for Disease Control in June 1981. To date, PHS has received reports of more than 14,000 cases. It is believed, however, that as many as one-half million to one million persons in the U.S. are infected with the AIDS virus. The case fatality rate among AIDS patients is high. Over 50 percent of reported cases have resulted in death.

The disease is further complicated by the fact that the virus has a long incubation period, the patient is affected by devastating disease specific complications and the disease is eventually fatal.

High Risk Groups include:

	% of Cases
. Sexually active homosexual and bisexual men with multiple partners	73%
. Intravenous drug users	17
. Persons having blood transfusions	2
. Hemophiliacs	1
. Heterosexual contacts of someone with AIDS	1

Some 6 percent of patients do not fall into these groups, but it is believed transmission occurs in similar ways. Infants and children who have developed AIDS have been exposed to the HTLV-III virus before or during birth, shortly thereafter, or have a history of transfusions.

Cases of the AIDS virus have been reported from 47 States and jurisdictions including Washington, D.C. and Puerto Rico. The highest concentrations of the disease, however, are in New York (36%) and California (23%). Florida, New Jersey and Texas also have high rates of the disease.

The four standard metropolitan statistical areas (SMSA's) with the highest concentrations of the disease are:

	# of Cases as of 11/11/85
New York	4,739
San Francisco	1,637
Los Angeles	1,252
Miami	462

There is a wide range of estimates as to the cost of caring for AIDS patients. The wide variation depends to a great extent on whether a hospital-intensive approach to care is taken, whether a continuum of care is offered which focuses on outpatient and residential care, the nature of the complicating disease associated with the immune deficiency, i.e., opportunistic infection or malignancy, and whether the patient is also an IV drug user.

For example, based on a cohort of 10,000 cases, CDC estimates $147,000 in inpatient hospital costs per AIDS patient. The San Francisco Health Commission estimates that the total cost of lifetime in-hospital treatment for an AIDS patient is $25,000 to $32,000 per patient. The emphasis on outpatient care in San Francisco is such that only 10% of San Francisco's AIDS patients are in the hospital at a given time. In New York, on the other hand, there has been a much more extensive use of inpatient care where a large number of the patients are also IV drug users.

CONGRESSIONAL INTEREST:

One indicator of Congressional interest in dealing with AIDS has evidenced itself in the proposed levels of funding in the pending FY 1986 Appropriation bill. Substantial increases are proposed for research and education efforts.

The Congress also has an interest in addressing the service delivery side of the problem. Given the high costs associated with inpatient care, there has been a recognition that there is a need for development and/or documentation of innovative, alternative approaches to managing patients with this disease. Congressional interest is in a greater focus on service delivery in community settings, as an alternative to inpatient care.

In the FY 1986 Appropriation bill (H.R. 3424), the Senate added $16 million for AIDS service demonstration projects. The bill language is as follows:

> "For necessary expenses...of which $16,000,000 shall be for the award of grants, under the authority of section 301 of the Public Health Service Act, for four projects demonstrating the delivery of health care services to victims of acquired immune deficiency syndrome, to be conducted by entities located, and providing services to persons residing, in those four standard metropolitan statistical areas having the highest concentration of persons suffering the syndrome."

The report language which accompanies the bill is as follows:

> "AIDS service demonstration projects
>
> The additional $16,000,000 appropriated to the Secretary is for four demonstration projects on the delivery of health care services to victims of AIDS. These demonstration projects are urgently needed for the delivery of health care services in community settings as an alternative to inpatient care in areas of high concentration of AIDS victims. Testimony received by the subcommittee at its September 26 hearing from the New York City Health and Hospitals Corp., indicated not only the expense of treating AIDS patients in the hospital (roughly $800 per day in New York City), but the need for community support and health care services. Many patients could be treated more humanely and at a lower cost in a community setting. For example, programs could be established for a hospice without walls, case management for IV drug abusers and education of IV drug abusers. The community care system demonstration and projects should be closely linked with the hospital so that a patient could easily move between the two settings as his/her disease progresses.
>
> The demonstrations set up by this section are intended to be used as models for other communities if this disease continues to spread."

KEY CONSIDERATIONS AND ISSUES:

In addressing the problem of providing health care services to victims of AIDS, there are several key considerations and issues:

(1) It is evident that the disease is spreading beyond the initial high risk groups and to a broader geographic base. The preferred approach therefore, is to treat this as an urgent public health problem in the sense that the emphasis is geared to protecting the health of the broader population as well as the victims of the disease.

(2) It is essential to develop a systematic case management approach that utilizes appropriate health care professionals, volunteers and a wide range of community supportive services. The concept of a continuum of care should underlie the approach to treatment since the disease

has a lengthy incubation period,is cyclic in nature with a number of acute espisodes, has a protracted chronic period and is eventually fatal.

(3) Cost-effective methods of treating the illness and meeting the needs of patients should be developed. Treatment in community settings as an alternative to costly inpatient hospital care should be sought.

(4) Demonstrations which are funded are intended to be used as models for other communities.

(5) Evaluation and tracking of costs should be an integral part of the demonstrations, so that success in meeting the objectives of cost-effectiveness and the replicability of the model can be evaluated.

(6) Consideration must be given to the full range of available financial resources to pay for the care of AIDS victims. Efforts to encourage private employers to allow for continuation or conversion of private health insurance benefits are essential. In addition, Medicare/ Medicaid coverage and eligibility should be examined to identify barriers to coverage and to determine if improvements are possible.

(7) Consideration must be given to the treatment of persons with AIDS Related Conditions (ARC), which can be severely debilitating, as well. ARC is characterized by a variety of chronic symptoms such as chronic generalized lymphadenopathy, recurrent fevers, weight loss, minor alterations in the immune system and minor infections which also require treatment.

PHS PERSPECTIVE ON PHASES OF THE DISEASE:

AIDS should be viewed from the perspective of the three phases of the disease, given the cyclic nature of the illness. AIDS patients experience many episodes of opportunistic infections and associated mental disorders such as anxiety, depression, thoughts of suicide, and a sense of social isolation.

The three phases of the disease are:

- o Public Health Phase
- o Episodic Acute Care Phase
- o Chronic Care Phase

The Public Health Phase should be viewed as the most critical phase of AIDS treatment since this phase has the greatest potential for maximizing the prevention and control of this disease. Many of the activities associated with this phase (testing, diagnosis, reporting, contact identification and follow-up) are critical and highly controversial. This phase is geared toward protecting the health of the broader population as well as the individual. It involves several essential activities:

- Diagnosis of AIDS and AIDS Related Complex (ARC)
- Reporting
- Contact identification and contact follow up.
- Counseling - including medical, psychiatric/psychological and financial
- Testing for HTLV-III antibody in blood banks and plasma centers
- Screening in selected areas, e.g., prisons, mental institutions, drug treatment centers, the military (e.g., the screening of all educational institutions such as those with residential housing arrangements, premarital and prenatal screening. Other special populations (e.g., immigrants and certain occupational groups, as appropriate) should also be included.

In order to implement the public health phase of care for this disease, a number of highly sensitive issues relative to public policy will be raised. Activities such as reporting, contact identification, contact followup and screening must be addressed, recognizing that reporting of positive tests to State Health Departments raises the issues of confidentiality, insurability and civil liberties. These issues must be resolved with the assistance of State and local authorities and health and scientific experts, if we are to proceed with the task of protecting the health of society, since approaches that are taken are significantly affected by local circumstances.

It is recommended that this phase follow the model developed by the PHS through its long history of experience and expertise in dealing with other sexually transmitted diseases. The public health approach should be integrated into the existing statewide and local public health systems, becoming a part of the ongoing surveillance system already established by CDC with state and local health authorities. Activities associated with this phase should also be integrated with CDC community-based demonstration projects for AIDS prevention and risk reduction. We do not anticipate that demonstration funds would be used to support this phase, since the CDC has been awarding funds to State and local health departments for a variety of Public Health/ AIDS-related activities.

The Episodic Acute Care Phase is characterized by the intermittent onset of acute illnesses, some of which may require hospitalization. There are likely to be a number of acute episodes during which disease-specific complications or concurrent illnesses require treatment. A recent study in San Francisco, for example, reveals an average of 1.7 admissions per AIDS individual in a 9-month period. During this phase the patient may still be able to take care of him/herself, physically and financially, but requires comprehensive, quality care from an interdisciplinary team of qualified and specialized health care professionals.

It is during this phase that appropriate inpatient resources must be made available to assure that optimum quality of care and services are provided in the hospital setting. Appropriate hospital facilities must be identified with highly specialized providers, adequate supplies and other

resources (e.g., laboratory, radiology). It is estimated in New York City, for example, that the nursing staff time alone, required for caring for AIDS patients is 2 to 3 times greater than the average for other patients.

The Chronic Care Phase follows one or more acute episodic illnesses. During this phase the patient's immune system is greatly compromised. The patient is often in a state of terminal illness and requires systematic, supportive care. Characterizing this phase are significant cost issues and concerns for both the patient and the health care system. During this phase, the patient may have lost his/her job and health insurance and may be totally or partially dependent. It is also during this phase that alternatives to costly inpatient hospital care are critical. The delivery of health care services in community settings as an alternative to inpatient hospital care should be the sought. Testimony received by the Subcommittee on Appropriations at a September 26 hearing from the N.Y. City Health and Hospitals Corporation indicated it costs approximately $800 per day for inpatient care in N.Y. City. The identification and development of appropriate alternative delivery modes of care such as the following should be pursued:

- specialized ambulatory clinics
- hospice care
- home health care
- semi-residential facilities - including selected employment opportunities
- nursing home care
- support services - psychological and psychiatric support services and counseling
- foster home care

FINANCING OF CLINICAL AND SUPPORTIVE SERVICES AND INCOME MAINTENANCE PROGRAMS

There has been some call for special health care financing programs dealing with AIDS, including revisions in Medicaid and other sources of financing indigent care. The Department feels that programs already exist that are supported by Federal, State and local resources that can be appropriately accessed to provide care for AIDS patients.

The attachment lays out some of the basics of these current financing mechanisms, including:

- Employer-Based or Private Health Insurance
- Medicare
- Medicaid
- Other Federal/State/Local Programs of Care
- Uncompensated Care

Since most health insurance in this country is employer-based, serious difficulties may begin for an AIDS patient if the person becomes unemployed. State laws which require continuation of health insurance for up to a year after leaving employment or which allow conversion to private health insurance are to be encouraged as one way to ease the burden of unemployment.

Gaining access to the Medicare and/or Medicaid programs is often difficult for the population groups with the highest incidence of the syndrome. Because approximately 91 percent of AIDS victims to date are males between 21 and 64 years of age, Medicaid services for the majority of sufferers would only be available through eligibility under Supplemental Security Income (SSI) as a disabled individual. In February 1985, AIDS was added to a list of presumptive disabilities, which hastens the eligibility determination for SSI and, in most States, Medicaid. One service problem is that under Medicaid law, hospice care is not currently covered.

With regard to Medicare, AIDS patients are not eligible unless they have been categorized and certified as disabled for a two-year period. Approximately 70 percent of the patients, however, die within the first two years of diagnosis.

In addition, Medicare coverage is not currently geared to cover long-term care services to meet the needs of AIDS patients who no longer require acute care in the hospital setting, but who need community based residential and supportive services.

Also included in the attachment is some information on Income Maintenance Programs managed by the Federal level:

- Supplemental Security Income (SSI) for Blind, aged and disabled (Title XVI of the Social Security Act)

- Disability Insurance Benefits (Title II of the Social Security Act)

Additional State/local welfare and social service programs offer additional support in terms of either income or supportive services.

RESOURCES AVAILABLE/RESOURCE GAPS BY GEOGRAPHIC AREA

Specialized AIDS resources will need to be identified at the local level. We have utilized the Area Resource File managed by the Bureau of Health Professions to develop printouts of overall data on demographic information and health care resources (e.g., number of general hospitals with selected services, number of nursing home beds) on those SMSAs with the highest concentration of those suffering with the syndrome. We currently have the files for New York, San Francisco, Los Angeles, and Miami, Florida SMSAs.

RECOMMENDATION:

If the demonstration funds are appropriated, PHS should publish a notice of availability of funds to solicit proposals from the four SMSAs of highest concentration of those affected by AIDS (New York, San Francisco, Los Angeles and Miami) to establish four demonstration projects. We should allow for the receipt of more than one application for consideration from

each of the four SMSAs. However, each SMSA would receive a single grant. Greatest consideration would be given, to those applicants who 1) demonstrate a model that provides for a consortium approach to providing a continuum of services to AIDS patients that includes State/local health departments, clinics, hospitals, HMOs, and other community facilities; and 2) give consideration in their approach to contiguous areas (i.e., outside the SMSA) with high concentration of AIDS victims such as Belle Glade, Florida and Newark, New Jersey. In addition greater consideraton will be given to those applicants which represent major public institutional systems, demonstrate the greatest degree of coordination and support of local government and demonstrate involvement of appropriate community organizations concerned with AIDS patients.

The proposed grantees should be required to design a community-oriented system of care for AIDS patients which covers a continuum of care from diagnosis to chronic care. San Francisco, for example, has a large network of AIDS-related community services. The San Francisco Aids Foundation coordinates prevention education projects, runs an AIDS hotline and arranges emergency housing and food services for patients. A special Godfather Fund provides personal care items for people with AIDS. A Home Care Hospice Program provides home care for patients in the final stages of AIDS.

Factors that will be considered in determining the specific allocation to each grantee include comprehensiveness of proposal and size of AIDS population.

TECHNICAL PROPOSAL:

The technical proposal developed by the proposed grantees must address the following:

Definition of the Problem and Background:

- Population demographics (including incidence of AIDS)
- Physical and financial resources currently available to AIDS patients.

Demonstration Design:

- How the grantee would go about establishing an organized systematic approach to managing the AIDS problem, which covers the Public Health, Episodic, and Chronic Care phases.
- Identification of resources including facilities, manpower and financing for patient care for each of the 3 phases of treatment for AIDS.
- How the grantee would develop a system for early diagnosis and detection, contact identification and contact followup.

- Description of a plan or methodology for screening in identified, selected sites.

- A method of maintaining confidentiality.

- Identification of range of alternative services that are available in the Chronic Care phase, making use of medical social workers, public health nurses, hospice models, and other resources appropriate to this level of care.

Organizational Approach:

- Extent to which proposed activities are coordinated with ongoing and planned activities sponsored by State/local health departments and other State and local agencies.

- Extent to which private and voluntary organizations involved and/or concerned with AIDS would be involved.

EVALUATION CRITERIA:

The following criteria should be used for evaluating proposals:

Definition of the Problem and Background:

- Degree to which the grantee accurately characterizes the problem in their geographic area.

- Degree to which grantee identifies local AIDS resources.

Demonstration Design

- Extent to which the grantee adequately identifies an approach to developing model standards of and approaches to care that can be replicated in other areas.

- Extent to which grantee addresses care for special populations, such as children with AIDS

- How well alternatives to inpatient hospital care are included.

- How well grantee demonstrates an approach to a cost effective system.

- How well grantee defines a system for tracking costs, so that judgments may be made about the costs of alternative approaches.

- How well grantee develops a method for evaluating the model program.

- Extent to which grantee demonstrates plans for continuing the model program at the end of the grant period, including financing from State and local sources.

- Extent to which grantee can demonstrate a more humane approach to patient management than existing modalities.

Organizational Approach:

- Extent to which the grantee demonstrates coordination of the proposed approach with ongoing and planned activities sponsored by Health Departments and other state and local agencies.

- Extent to which grantee provides for community participation, e.g., local advisory groups.

REVIEW PROCESS:

It is recommended that an Ad Hoc technical review panel be convened of 3-4 federal representatives (e.g., NIH, CDC, HCFA, HRSA, OASH) and 6 outside experts representing finance, medicine, hospice care providers, State/County Health officials and community-based organizations. Resource persons with expertise in AIDS related research, the provision of care, education and the psychological aspects of AIDS should be invited.

Financial Resources for Health Care and Income Maintenance

Acquired Immune Deficiency Syndrome (AIDS)

I. Financial Resources for Health Care

One of the problems associated with AIDS is a lack of financial resources to pay for what is often a very costly illness. Because of the nature of the disease, costs are incurred in both the episodic acute care phase and in the chronic care phase. The episodic acute care phase is characterized by the intermittent onset of acute illnesses, some of which may require hospitalization. There are likely to be a number of acute episodes during which disease-specific complications or concurrent illnesses require treatment. In the chronic care phase, the patient is often in a state of terminal illness, and requires systematic, supportive care. During this phase, the patient may have lost his/her job and health insurance and may be totally or partially dependent. Provided below is a summary of some of the major financial resources for health care, as well as some of the AIDS-specific problems with those resources.

A. EMPLOYER-BASED OR PRIVATE HEALTH INSURANCE

Recent estimates of health insurance coverage include the following:

- The Census Bureau estimates that 15% of the total U.S. Population-- 35 million persons -- was uninsured, lacking either public or private health insurance. The population aged 16-24 is the age group most likely to be uninsured. Levels of uninsurance are higher in the South and West than in other areas of the country. Blacks and Hispanics are more likely to be uninsured than Whites.

- The National Medical Care Expenditure Survey (1977 NMCES) identified 12.6% of the American popualtion as being without health insurance.

- NMCES data show that 85% of the privately insured population receives its insurance coverage as a fringe benefit of employment.

- In 1977, of the estimated 6.5 million persons unemployed, 74% retained their insurance coverage throughout the year, 8% lost their private insurance coverage, 7% obtained other part-year insurance coverage from other sources, and 11% were uninsured even when employed.

- Although employment increases the likelihood of health insurance coverage, it is not a guarantee of its availability. Over 9 million of the 17 million Americans uninsured in 1977 were employed, 6.4 million full-time. Employees of small firms, farms or non-union companies tend to have lower rates of insurance coverage.

- Individuals with insurance coverage may become medically indigent depending on the extent of illness. NMCES provided an intermediate estimate that 13% of the privately insured population under age 65 is underinsured.

AIDS-Specific Problems

A major problem for AIDS patients is the possibility of losing their health insurance. This occurs either when they are too ill to continue working, or in some cases employers concerned about medical bills have begun to discharge persons with AIDS who are still able to work.

- To deal with the problems resulting from unemployment, a number of States have mandated continuation and/or conversion of private health insurance benefits in the event of certain occurrences. Continuation of benefits allows individuals who lose employment and who were previously covered under a group policy to continue coverage at the lower group rate for a specified time period. With conversion privileges, insurers are prohibited from refusing to allow individuals losing group health insurance coverage to convert to individual coverage.

- A few States have adopted policies to aid individuals identified as "high risk" by insurance companies, and who consequently have difficulty in obtaining private insurance. States such as Connecticut have established statewide risk pools for such individuals, made up of all the insuring organizations within the State.

Private insurance is generally geared to acute care rather than long-term care. Private health care policies generally do not cover long-term stays.

Although there have been recent efforts to develop nursing home insurance, this is still a limited area. Recent estimates are that approximately 100,000 people have such coverage. Insurers may reject applicants because of existing illnesses, daily benefits are usually paid at a fixed amount, even if the nursing home charges more, and payments typically run out after one to four years.

Another set of potential problems has to do with eligibility to purchase insurance. Some insurance companies (mostly life insurance) have proposed screening to test for th HTLV-III blood antibody. To the extent such screening comes into effect with consequent denial of insurance, a greater proportion of costs are shifted to individual hospitals or public funds.

B. MEDICARE

Eligibility

Medicare is a Federal health insurance program for most aged and certain disabled individuals who qualify for Social Security cash benefits. An individual with AIDS can be eligible for the Medicare program if he/she is:

- Age 65 or over and eligible for Social Security payments or enrolled on a premium-pay basis under Parts A or B of Medicare.
- Under 65 and eligible for the Social Security Disability Insurance (DI) Program; or
- Afflicted with End Stage Renal Disease

The standards for determination of disability under the DI program are identical to those under SSI. Because the program is targeted to the long-term disabled population, newly entitled DI beneficiaries do not receive Medicare until they are on the roles for two years.

Services

Health Services are covered in two parts:

- Hospital Insurance (Part A) helps pay for inpatient hospital services which may include a semi-private room, meals, regular nursing services, operating room, special care units, drugs and medical supplies, laboratory tests, and rehabilitation services.
- Medical Insurance (Part B) covers physicians' services, outpatient hospital services, diagnostic tests, outpatient physical therapy, speech pathology services, medical equipment and supplies and home health services.

AIDS patients who are entitled to Medicare are eligible for the same range of services and benefits that are available to other segments of the Medicare population. Benefits that would typically be utilized by an AIDS patient include, under the Medicare Part A hospital insurance program, inpatient hospital care, medically necessary inpatient care in a SNF after a hospital stay, hospice care, and home health care. Part B of Medicare would help pay for doctors' services, outpatient hospital care, outpatient physical therapy and speech pathology services, home health care, radiology and laboratory services, and a variety of other health services and supplies which are not covered by the Part A program.

In terms of long-term care, Medicare covers certain elements of this:

. Skilled Nursing Facilities (SNFs) - Medicare is designed as an acute care program. Benefits are designed to be part of the continuum of care in an acute episode, either following hospital care, or as an economical substitute for an extended hospital stay. Consequently the SNF benefit is not designed for long-term stays.

  The skilled-nursing benefit covers only short-term post acute care for persons needing skilled-nursing or rehabilitative services in an inpatient setting. The recent average Medicare coverage of a SNF stay was 30 days, much less than the average stay of 456 days for all nursing home patients.

. Home Health - Under the Medicare home health benefit, the following types of services are covered:

  - Part-time or intermittent nursing care provided by or under the supervision of a registered professional nurse

  - Physical, occupational, or speech therapy

  - Medical social services

  - Part-time or intermittent services from a home-health aide

  - Medical supplies and medical appliances

Passage of the Omnibus Reconciliation Act in 1980 expanded the home health benefits by removing the limit on the number of covered home-health visits, eliminating the requirement for a prior hospital stay, eliminating the deductible, and allowing more proprietary home-health agencies to participate in Medicare.

. Hospice care

  Medicare Hospital Insurance can help pay for hospice care if the following conditions are met:

  - A physician certifies that a patient is terminally ill

  - A patient chooses to receive care from a hospice rather than standard Medicare benefits for the terminal illness.

  - Care is provided by a Medicare-certified hospice program.

Hospital insurance can pay for a maximum of two 90-day periods and one 30-day period.

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AIDS-Specific Problems

- Currently AIDS patients are not eligible for Medicare unless they have been categorized and certified as disabled for a two-year period. Approximately 70% of the patients, however, die within the first two years of diagnosis.

  This is reflected in the payor mix of AIDS patients treated by the Health and Hospitals Corporation in New York, in which 1% was Medicare.

  One suggested approach in recent Congressional testimony is that Medicare eligibility should be established at the time of diagnosis. This would eliminate the two-year waiting period for AIDS patients.

- Medicare coverage is not currently geared to cover long-term care services to meet the needs of AIDS patients who no longer require acute care in the hospital setting, but who need continued care in the home or in a structured residential setting. Medicare coverage for skilled nursing facility care and home health care is largely restricted to short-term, post-acute care for the elderly.

- Medicare reimburses hospitals for care rendered to a patient on a prospective basis, with the amount of reimbursement based on a diagnostic code. As DRGs are currently constituted, cases positively identified with AIDS diagnosis fall into DRGS 398 (Immunity Disorders, Age over 69 and/or complications) and DRG 399 (Immunity Disorders, Age under 70 with complications). The resource intensity weights of these DRGs are .9753 and .7247 respectively. Resource intensity weights reflect hospital resources necessary to treat the average patient in a given DRG. Overall, resource intensity weights are set at 1.0 for the average patients. Thus average resources required by patients in DRGs 398 and 399 are supposedly less than those required by the average hospital patient. In reality, the AIDS patients are much more resource intensive.

  Other problems in DRG classification occur when the principal diagnosis is one of the opportunistic infections occasioned by AIDS. Most frequent among these is pneumocystis carinii and Kaposis sarcoma. Similar problems with resource intensity exist.

C. MEDICAID

Eligibility

Medicaid is a joint Federal and State-financed, State-administered entitlement program which pays for the health care of certain specific categories of low-income people.

Medicaid is available to:

- All persons who are receiving payments under the Aid to Families with Dependent Children program
- The aged, blind, and disabled who receive Supplemental Security Income
- Approximately 30 States also cover people who are medically needy but whose incomes exceed qualifications for welfare.

Because approximately 91 percent of AIDS victims to date are males between 21 and 64 years of age, Medicaid services for the majority of sufferers would only be available through eligibility under SSI as a disabled individual.

To be considered disabled under the SSI program, a person must have a physical or mental condition which prevents him from doing any substantial gainful work, and which is expected to last (or has lasted) for at least 12 months or is expected to result in death. When determining eligibility for SSI, the Social Security Administration (SSA) will find an applicant presumptively disabled if a person's condition meets or equals the severity of a similar condition described in its Listing of Impairments. In February 1985, AIDS was added to this list of presumptive disabilities. The presumptive disability process significantly hastens the AIDS sufferer's eligibility determination for SSI and, in most States, Medicaid.

After disability is established, certain income and resource criteria must be met before both SSI cash benefits and Medicaid benefits are provided. Thirty-six States automatically provide Medicaid to SSI cash recipients; 14 states require SSI cash recipients to meet more restrictive criteria such as lower resources or income ceilings than SSI, different family income rules, or more stringent definitions of disability, in order to be eligible for Medicaid.

Services

The scope of covered services under Medicaid varies considerably from State to State. All States must cover certain mandatory services for the categorically needy and, for all practical purposes, for the medically needy. Mandatory services which would most likely be utilized by AIDS patients are inpatient hospital services, outpatient hospital services, rural health clinic services, other laboratory and radiology services, skilled nursing facility (SNF) services, and home health care for individuals aged 21 and over.

States may also choose to cover additional services as specified in federal regulations. Some examples of optional services offered include clinic services, prescribed drugs, intermediate care facility services, miscellaneous diagnostic services, skilled nursing facility and home health services for individuals under 21 years of age, and other ancillary services such as personal care services, private duty nursing, private practitioners' services, and rehabilitation services. Nearly half the States offer 20 or more additional services;

California and New York, which have recorded almost 60 percent of all AIDS cases in the United States, offer 30 and 29 optional services, respectively, to their Medicaid populations. Through home and community-based waivers, States can also cover a wide array of noninstitutional long term care services that are not otherwise offered. Under current Medicaid law, States are not permitted to offer hospice services. However, with the wide range of optional services offered by States, many hospice-related services may be made available to AIDS patients.

With regard to long-term care services more specifically, approximately half of Medicaid expenditures are for long-term care for the elderly and disabled.

(1) SNF's - States must cover services provided in skilled nursing facilities, the most intensive form of nursing home care, for persons 21 years of age or over. States may cover SNFs for persons under age 21 at their option (44 States and D.C.)

(2) Intermediate Care Facilities (ICFs) - this less intensive form of nursing care is a State option, but is covered in 49 States and D.C.

(3) Home Health - States must cover home-health services to persons 21 years of age or over, and to those persons under 21 years of age if the State provides SNF services to that age group. In addition, States may cover the following optional services:

- Private duty nursing (19 States and D.C.)
- Personal care (20 States and D.C.)
- Noninstitutional LTC services of a non-medical nature (e.g., case management, homemaker/chore, adult day care) as part of a home and community-based waiver.

It is estimated that approximately half of all Medicaid recipients in nursing homes were not initially poor, but "spent down" their income and resources as a result of the high cost of nursing home care. All Medicaid nursing home recipients must contribute all of their income except for a small personal needs allowance ($25 in most States) to the cost of their care.

AIDS-Specific Problems

- The potential importance of Medicaid as a payor for AIDS patients is reflected in the payor mix of AIDS patients treated by the Health and Hospitals Corporation in New York. Approximately 65% of the patients were covered in part by Medicaid.
- Hospice care is not currently covered under Medicaid.

- If the hospice benefit were extended to Medicaid patients, some testimony proposed that eligibility restrictions should be eased and the reimbursement ceiling raised.

- Encouragement could be given to the use of waivers under Section 2176 Home and Community-based Services. These waivers allow States to amend their Medicaid plans to include coverage for certain community services for defined populations as long as the cost of the service package does not exceed 100 percent of the equivalent costs in an institution.

D. OTHER FEDERAL/STATE/LOCAL PROGRAMS OF CARE

1. Social Services Block Grant Funds (Title XX of Social Security Act) - Many States use these block grant funds for homemaker and chore services. Small amounts are spent for monitoring services, adult day care, and foster care homes.

2. Personal Care and Domiciliary Care Facilities - A personal care home provides personal care services, including assistance with activities of daily living (ADL) such as bathing, eating, transferring, and ambulation. Most homes are proprietary.

   A domiciliary care facility provides a lower level of care -- room, board, housekeeping, supervision, and some degree of ADL assistance. These facilities, which are commonly licensed by State departments of social services, are not usually allowed to provide medical services.

   Personal and domiciliary homes are not covered under either Medicaid or Medicare. They may, however, receive public payments from the Supplemental Security Income (SSI) program, which provides cash assistance to aged, blind and disabled. Recipients may purchase congregate or personal care with the money.

3. State/Local Programs of General Assistance

   A number of States and/or local governments have established programs to finance health services for poor individuals unable to qualify for Medicaid, under the heading of general assistance medical care.

   A few States have developed catastrophic health insurance programs. These include Alaska, Maine and Rhode Island.

4. Revenue Pools

   A few States have initiated revenue pools which are used to finance indigent care. In New York, funds are derived from a surcharge levied on hospital reimbursement amounts paid to insurers. The pool funds are redistributed to individual hospitals to offset charity care losses. In Florida, revenues are

generated by a tax on each hospital's net revenues. The funds are used, in part, to pay for a major portion of the State contribution required to finance the medically needy program.

5. Higher Levels of Medicaid Reimbursement for Certain Hospitals

States are given increased flexibility under their Medicaid programs with the Omnibus Budget Reconciliation Act of 1981. New Medicaid approaches were required, however, to take into account the situation of hospitals serving a "disproportionate number" of low-income patients. These provisions provide States with an opportunity to direct funds to those hospitals which provide care to those unable to pay. Not many States have made extensive use of this approach to date.

6. Direct Financial Support to Hospitals

In addition to direct support for the operation of public hospitals, some States also have developed direct subsidy programs. Colorado has established a Medically Indigent Program in which direct payments are provided to hospitals to fund health care for uncovered individuals. California has established a County Health Services Fund which provides grant money and matching funds to counties for the provision of indigent care.

E. UNCOMPENSATED CARE

Uncompensated care represents the debt incurred after services are delivered but no (or inadequate) payment is made. It is the total costs of care delivered to:

- Medically indigent for which there is no public reimbursement.
- Medically indigent for which there is inadequate public reimbursement.
- Bad debt incurred when patients do not, but presumably can, pay their bills.

Community hospitals provided $7.5 billion in uncompensated care in 1982. Of the $7.5 billion, $2.3 billion or 31% was reported as charity care. The balance, $5.2 billion resulted from bad debt. These figures are based on hospital charges and not the actual costs of uncompensated care from the AHA 1982 Annual Summary.

Hospitals with certain characteristics have especially high levels of uncompensated care. For example:

- Major public teaching hospitals account for 5 percent of aggregate total charges but 21 percent of uncompensated care.
- Southern large city public hospitals account for 2 percent of aggregate total charges and 12 percent of uncompensated care.

In short, public hospitals are bearing a disproportionate share of the uncompensated care burden.

II. Income Maintenance Programs

Major Federal programs which may potentially be used to provide income maintenance for AIDS victims include the following:

A. Supplemental Security Income for the Aged, Blind and Disabled

Under Title XVI of the Social Security Act, individuals who:

- have attained age 65, are blind or disabled
- have limited income and resources in accordance with the provisions of this title
- do not have sufficient Social Security coverage to be eligible for Disability Insurance Benefits

are eligible for Supplemental Security Income (SSI).

An individual is considered disabled if unable to engage in any supplemental gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

States may make supplementary payments to those eligible for Federal SSI payments.

AIDS was made a "presumptive disability" under SSI in February 1985. The presumptive disability process significantly hastens the AIDS sufferers eligibility determination for SSI and, in most States, Medicaid.

B. Disability Insurance Benefits

Under Title II of the Social Security Act (Section 223), individuals who:

- are insured for disability insurance benefits (by specified payments into Social Security)
- have not attained retirement age
- are under a disability

are entitled to a disability insurance benefit.

Disability is defined as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death of which has lasted or can be expected to last for a continuous period of not less than 12 months.

Entitlement to Hospital Insurance Benefit - An individual who has not attained age 65, and who has been entitled to disability insurance benefits for 24 months, is entitled to hospital insurance benefits under Part A of Medicare (Title XVIII).

This 24 month waiting period makes it difficult for AIDS patients to gain Medicare eligibility under this program.

Mr. WAXMAN. I would like to read you a bit from some of the materials that we obtained from the Department. In these documents HRSA has said, and I quote:

> There has been a recognition that there is a need for development and or documentation of innovative approaches to dealing with this disease. Greater focus needs to be placed on treatment in community settings with greater scrutiny given to extensive inpatient care.

Do you agree with that statement?

Mr. KELSO. If that is in the proposal we sent to the Assistant Secretary, I would agree with it. I don't know where that came from.

Mr. WAXMAN. That's correct. It is a statement from that document.

In developing these draft proposals, did your staff work with HCFA staff to test ways to make Federal Medicaid and Medicare Programs work in this model?

Mr. KELSO. I don't think we got to that point. We have worked with Mr. Smith. He is on our work group, but I don't think at that point in time we had gotten that far.

Mr. WAXMAN. In your best professional judgment do you or any of your staff have any substantive reservations about the need to develop alternative care models for treating people with AIDS?

Mr. KELSO. Mr. Chairman, if that legislation, the money is available, we will spend it.

Mr. WAXMAN. I have no doubt that you would spend any money that we would make available to you, but I am just asking: In your judgment do you—and maybe Dr. Martin or Dr. Manley can comment on this—do you have any reservations about the need for developing these alternative care models?

Dr. MARTIN. I think the question is not about the need or the character of the type of services, but I think the administration's position has to do with specifically the role of the Federal as opposed to local and State government in funding it. I think there is consensus on the need for other than hospital services.

Mr. WAXMAN. So, you have no doubt that we need to look at alternatives to hospital services for AIDS patients. It's something we need to do as we look at how the whole health care system is going to deal with AIDS?

Dr. MARTIN. I think there is a clear consensus on that.

Mr. WAXMAN. Does anybody disagree? Dr. Manley? Mr. Kelso?

Mr. Smith, I have a couple of questions from your testimony.

First, you suggest that 40 percent of AIDS patients are receiving Medicaid benefits. Can you tell me the source of that number?

Mr. ELMER SMITH. The source of that number is from our HCFA actuaries. They in turn have relied upon some limited data, because limited data are all that are available, Mr. Chairman. There are no data available through the comprehensive broad-scale data systems that are used in the Medicare/Medicaid Programs because they do not have information down to the level of diagnosis that would enable us to develop these numbers.

So, they have been developed from published reports. They have been developed from conversations with people who are providing care and agencies that are administering care in some of the cities with the largest incidence of AIDS. It is an attempt to put together

the best possible estimate we can make based upon these limited data.

For this reason, our HCFA actuaries are unwilling to project any costs at this time beyond fiscal year 1986 because of the rapidly changing picture, both in terms of numbers of cases and also in terms of the fact that many communities are now moving in the direction of community-based care. They are moving more strongly in that direction.

Mr. WAXMAN. Could you provide for the record the backup of the calculations?

Mr. ELMER SMITH. I would be glad to, Mr. Chairman.

Mr. WAXMAN. The way you came to the conclusion that 40 percent of AIDS patients are receiving Medicaid benefits.

The detailed methodology for deriving the estimates of the costs of health services borne by the Medicaid Program is discussed in the attached paper developed by actuaries of the Health Care Financing Administration.

[Testimony resumes on p. 113.]

[The information referred to follows:]

PRELIMINARY ESTIMATE OF THE IMPACT OF AIDS ON THE MEDICAID PROGRAM

The following estimates were based on information available to us on October 28, 1985. We are presenting this paper not only for its informational value but also to highlight certain questions which need to be answered if better estimates are to be made.

In our opinion the Federal Medicaid cost due to AIDS is:

FY	1985	1986
$millions	50	100

The above amounts have been rounded to the nearest $25 million. They represent Federal costs only. Aggregate State Medicaid costs for AIDS are roughly equal to Federal Medicaid costs.

In addition, these costs do not include:

a) the costs to States and localities for costs beyond Medicaid reimbursement levels,

b) the costs to States and localities for indigent AIDS victims who do not qualify for Medicaid,

c) the total cost of providing care to AIDS victims (however an estimate of the total cost,derived from our estimates, is $450 million in FY 85 and $850 million in FY 86),

d) the costs for providing care to victims of AIDS-related complex - ARC (data on ARC is even harder to come by than data on AIDS; it should be noted that while an AIDS victim is presumptively disabled for federal disability purposes,the same is not true for an ARC victim.) and

e) the cost of AIDS research.

Since Medicaid data on AIDS was not available, the above amounts were developed by:

1)Estimating the total average annual AIDS population.
(6204 in FY85 and 10682 in FY86)

2)Estimating the fraction of the total AIDS population which is covered by Medicaid.(40%)

3)Estimating the annual number of days of hospitalization.(90)

4)Estimating Medicaid reimbursement per hospital day.
($501 in FY85 and $527 in FY86, with an average Federal share of 51.4%)

5)Ignoring non-hospital costs.

To the extent possible a number of independent estimates of each of the above was developed and an effort was made to rationalize significant differences. However we were not completely successful and some estimates had to be based on our own judgment taking into consideration available data. The estimates are discussed in more detail below.

1)The total average annual AIDS population.

The Center for Disease Control in Atlanta very generously shared their data with us. This data was adjusted for reporting lags and then used to determine the number of living AIDS victims at semi-annual intervals projected thru 12/86. We could not project these numbers very far into the future at this time with any confidence because of our lack of understanding of the rate of change of the incidence of AIDS. A more detailed discussion of this aspect of the estimate is attached.

2)The Medicaid fraction of the total AIDS population.

Two people, one in San Francisco and one in New York, estimated that Medicaid was the payor for about 2/3 of the AIDS patients in their public hospitals. One of these and a third person felt that the public hospitals saw about 1/3 of the AIDS patients and that Medicaid was the payor for about 1/3 of the balance. The other person felt that the public hospitals saw more than 1/3. These observations imply that Medicaid is the payor for over 44% of AIDS patients. This number may be overstated for three reasons. First, there may not be as good a network for assisting people to get on Medicaid outside of major metropolitan areas. Second, it may be more difficult to qualify for Medicaid outside of New York and California. Third, there may be an overcount of the people who convert from private pay to Medicaid.

Another approach to estimating the fraction comes from looking at the number of people living who received disability awards because of AIDS.

The AIDS diagnosis has been treated as presumptive disability for Titles II and XVI. Title XVI qualifies people for Medicaid immediately. Title II qualifies people for Medicare but only after a 24-month waiting period. In the interim these people and others may become eligible for Medicaid through the medically needy program in thirty States. The data on awards does not include information on medically needy AIDS cases. Comparing the number of living AIDS awards against the total AIDS population alive at the same time gives a ratio of about 30%. This number has to be increased because of the additional AIDS victims who would qualify for Medicaid (through the medically needy or some other program) and those who were already on Medicaid when they contracted the disease.

Both of the above observations are consistent with a ratio of 40%.

3)The annual number of days of hospitalization.

Knowledgeable experts differ widely on this number, from a low of 30 days to a high of almost 180 days. The low numbers may represent distinct regional practice and may also mask significant expenses from out-patients and alternative institutions. The high numbers also represent distinct regional practice where there is a lack of treatment alternatives; moreover, they are based on a study which may have significant design flaws and may not reflect current practice.

A point prevalence study done in New York State about a year ago found 21.3% of living AIDS victims in a hospital on a specific day. While this number may also suffer from reporting problems, it does not suffer from major design problems except for the fact that it represents just one data point. It is interesting to note that in this study the New York City percentage was a little lower while the upstate percentage was somewhat higher. It is not unlikely that hospitalizations are longer in areas where AIDS is relatively infrequent. Since AIDS is spreading into newer areas, we could expect that the lower numbers from California and possibly even New York City will be offset by higher numbers from the rest of the country.

In our judgment the best estimate, at this time, is 90 hospital days per year.

4)Estimating Medicaid reimbursement per hospital day.

Most knowledgeable estimators agree that AIDS patients are expensive, costing between $800 and $850 per hospital day. However, maximum Medicaid reimbursement levels are usually lower than that. In addition, Medicaid reimbursement varies markedly from State to State. Since the incidence of AIDS and Federal matching percentage also vary by State we have developed a weighted average hospital cost per day. In doing so we kept the State distribution of AIDS victims constant over the period of our estimate. This is another reason why we cannot project too far into the future.

5)Ignoring non-hospital costs.

Except for California, non-hospital costs are probably small in comparison to hospital costs and fall within the error of the estimate. Ignoring California's non-hospital costs may be offset by fewer hospital days per year being used in California than is included in our estimate.

More importantly good data on non-hospital costs could not be developed at this time.

DEVELOPMENT OF AIDS POPULATION USING CDC DATA

In developing the projected surviving AIDS population over time, we took the following steps:

1) Estimating New Cases.

CDC sent us a machine-readable extract from their AIDS database containing key variables for the 14,288 AIDS cases reported through 10/21/85. These variables included date of diagnosis, date of report to CDC, and date of death. From this data we created a SAS dataset, which was used for all our subsequent analyses.

Our first task was to adjust the CDC data for reporting lags using the technique of an actuarial claim lag study. From a matrix of cases arrayed by month of diagnosis and month of report we developed, for each month following diagnosis, the average percent-of-cases-reported, also known as "completion" or "lag" factors. (For this calculation we excluded approximately 200 observations with lags less than zero or greater than 20 months.) To adjust for reporting lags the number of cases diagnosed in a given month and reported through a given date is divided by the appropriate completion factor. The actual factors used for subsequent calculations were adjusted to a half-year basis and are given below.

This lag investigation revealed that the average reporting lag for cases reported through 10/21/85 is 3 months with a standard deviation of about 4 months. The completion factors derived were as follows:

Half-Year Prior to a Given Date	Percent of Cases Diagnosed in Half-Yr Which are Reported by Given Date
1	83.7%
2	94.4%
3	98.9%
4+	100.0%

2

The second step in developing new case data was to construct a mathematical model of growth in new cases using the completed CDC data and then to use this model to project new cases into the future. We used an exponential growth equation in which the growth rate could be varied over time. Through trial and error adjustment of its parameters we were able to obtain a fairly good fit to the completed CDC data for cases diagnosed through 6/30/85. The resulting equation was then used to estimate new cases for the last half of 1985 and calendar year 1986. The following table compares actual data to that obtained from our model:

Half-Year of Diagn.	New Cases- CDC Data	New Cases- Model Data
1-6/80	18	28
7-12/80	29	60
1-6/81	87	122
7-12/81	173	230
1-6/82	359	406
7-12/82	631	678
1-6/83	1184	1070
7-12/83	1525	1606
1-6/84	2356*	2304
7-12/84	3133*	3168
1-6/85	4283*	4194
7-12/85		5366
1-6/86		6659
7-12/86		8042

* Adjusted for reporting lag.

2) Estimating Survivors.

For the new AIDS cases diagnosed in each half-year, as developed in step 1), we next calculated the expected number of survivors at the end of half-year intervals, using mortality rates derived from analysis of the CDC data and conversations with CDC staff.

A study of the data would indicate that deaths are probably under-reported. The survivor rates we used, which are shown below, thus represent a combination of data analysis and informed judgment:

Half-Yr from Diagnosis	Fraction of AIDS Victims Surviving
1	.72
2	.50
3	.33
4	.20
5	.09
6	.00

These rates were applied to each group of new cases by half-year of diagnosis to obtain survivors for each group at subsequent semi-annual intervals. The resulting matrix of surviving AIDS victims was then summed over all diagnosis months to obtain a table of estimated numbers of AIDS victims living at semi-annual intervals, projected through 12/31/86. This table is shown below compared with the same numbers calculated from CDC data:

Date	-- AIDS victims living -- Model Projection	CDC data
6/30/80	31	26
12/31/80	47	39
6/30/81	107	92
12/31/81	221	181
6/30/82	458	403
12/31/82	853	795
6/30/83	1594	1546
12/31/83	2392	2291
6/30/84	3634	3457*
12/31/84	5128	4879*
6/30/85	7097	6440*
12/31/85	9322	
6/30/86	11885	
12/31/86	14737	

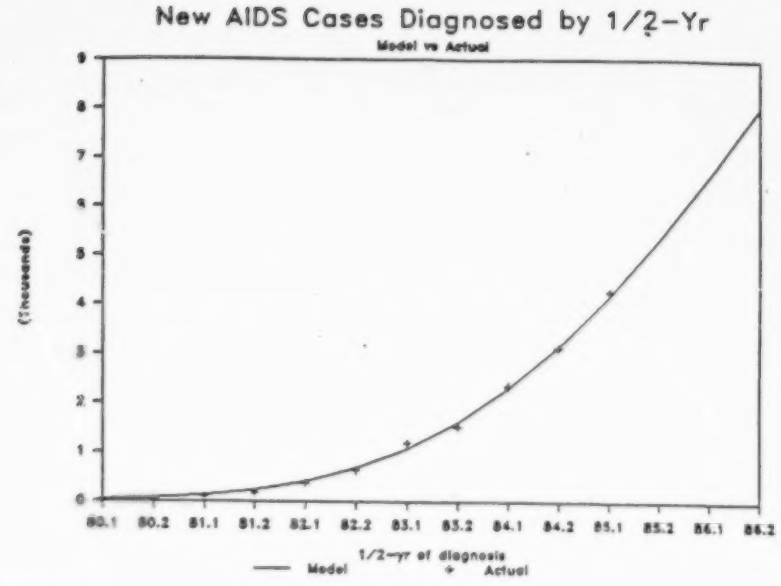
* These numbers are low because of reporting lags.

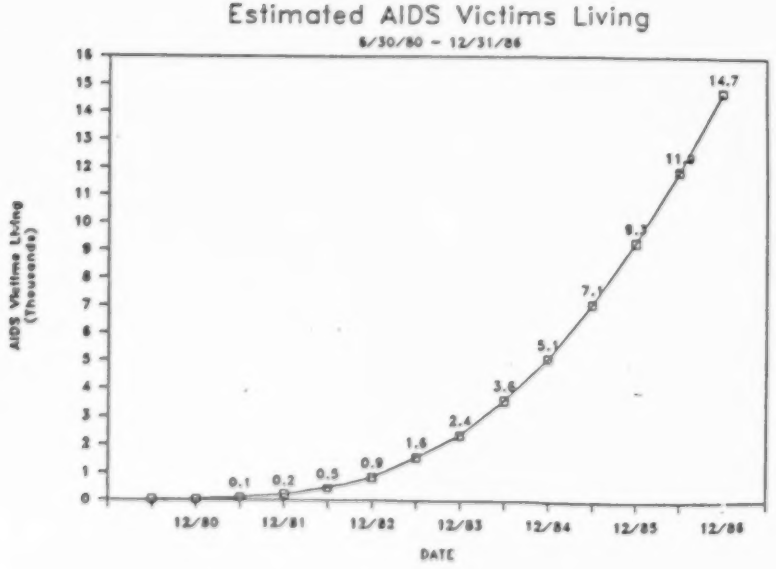
3) Calculating Exposures.

Because our goal was to estimate the amount of Medicaid expenditures made on behalf of AIDS victims, we next made estimates of the number of AIDS person-years, or exposures, by Federal fiscal year. The survivor data from step 2) were interpolated to a fiscal basis, and the number of half-years of exposure for each half-year was taken to be the mean of the beginning and ending population for that half-year. The following table shows the results of this calculation:

Federal Fiscal Year	AIDS Person-Years
84	3100
85	6204
86	10682

Note: Because of uncertainty concerning future changes in the rate growth of AIDS cases and medical advances which affect the length of the life of AIDS victims we do not feel that our methods should be used to project the AIDS population beyond 1986.


New AIDS Cases Diagnosed by 1/2-Yr
Model vs Actual
(Thousands)
0
1
2
3
4
5
6
7
8
9
80.1
80.2
81.1
81.2
82.1
82.2
83.1
83.2
84.1
84.2
85.1
85.2
86.1
86.2
1/2-yr of diagnosis
Model
Actual


Estimated AIDS Victims Living
6/30/80 - 12/31/86
AIDS Victims Living (Thousands)
0
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
0.1
0.2
0.5
0.9
1.6
2.4
3.6
5.1
7.1
9.3
11.6
14.7
12/80
12/81
12/82
12/83
12/84
12/85
12/86
DATE

THE FOLLOWING ARE HCFA GUIDELINES

FOR STATES APPLYING FOR FREEDOM

OF CHOICE WAIVERS UNDER 1915(b)

OF THE SOCIAL SECURITY ACT

(SECTION 2175 WAIVERS)

2105. GENERAL REQUIREMENTS FOR WAIVER REQUESTS UNDER SECTION 1915(b)

A. HCFA will consider only waiver requests submitted by or through the Governor, State cabinet members responsible for State Medicaid agency activities, the director of the State Medicaid agency, or by someone with the authority to submit waiver requests on behalf of the director.

Waiver requests generally are submitted by States to HCFA regional offices. The requests are reviewed initially at this level and then forwarded, along with the regional office's recommendation, to HCFA central office for further review. Final approval or disapproval of the application is made by the HCFA Administrator, although disapprovals must have the concurrence of the HHS Secretary.

A waiver request must be approved, disapproved, or additional information requested within 90 days of receipt or else the request will be deemed granted. If additional information is received, the waiver request must either be approved or disapproved within 90 days of receipt of the information. Section 1915(b) waivers are approved for a 2-year period. Upon the State's request, the waiver may be renewed for an additional 2-year period (1915(d)). (See section 2109)

B. A waiver request must state:

1. Under which 1915(b) provision(s) the waivers are being sought (see section 2107;

2. Which sections of 1902 of the Act must be waived, and the reasons for waiving them;

3. A discussion of the purposes of the waiver request;

4. A complete description of the program, including such areas as services to be provided, types of providers, methods of payment, whether participation is voluntary or involuntary, grievance procedures, numbers of beneficiaries anticipated in the program, and areas of the State in which the program will be implemented.

C. In applying for a waiver, a State must adequately document and maintain adequate data regarding those criteria explained in section 2108.

D. No waiver may be granted for a period longer than 2 years; however, a State may request an extension of the initial waiver.

E. Recipients must have reasonable access to services, taking into consideration such factors as geographic location, travel time, and provider/recipient ratios.

F. A State must assure that there will be no restriction on recipients' access to emergency services.

2106. COORDINATION WITH HCFA REGIONAL OFFICE

A. Preparing the waiver request.—A State is encouraged to contact the HCFA regional office staff for guidance in preparing waiver requests in accordance with statutory and regulatory requirements. Regional office assistance during the planning of the proposal and review prior to submission of the proposal, will help to resolve problems in the early stages and will aid in the expeditious processing and approval of the waiver. In addition, the regional office staff is aware of the types of programs that are being proposed and implemented by other States, and this information could be useful in your program.

B. Submitting the waiver request.—States are encouraged to submit the waiver request to the regional office. (See section 2105).

C. Modifying the implementation date.—In the event that a State loses a significant amount of time between the approval of its waivers and the actual date of implementation, and it wishes to modify the implementation date to allow the waiver a full 2-year term, notify the regional office. Include in this written request the reasons for the delay, and the preferred date of implementation. The regional office will forward this request to central office, along with its recommendation.

D. Submitting request for extension.—Submit requests for the extension of the waiver through the regional office. (See section 2109)

2107. WAIVER CATEGORIES

A waiver may be granted only for one or more of the categories listed below.

A. Primary Care Case-Management System or Specialty Physician Services Arrangement (Section 1915(b)(1)).—Section 1915(b)(1) allows States to implement primary care case-management systems or specialty physician services arrangements. Under these programs, a State may restrict the provider from or through whom a recipient can obtain medical care services. Restrictions may not apply to emergency services, nor may access to services of adequate quality, where medically necessary, be impaired.

Under a primary care case-management system, a State must assure that a specific person or persons or agency will be responsible for locating, coordinating, and monitoring all primary care and other medical care and rehabilitative services on behalf of a recipient. Primary care includes a range of services adequate for meeting the great majority of personal health needs. Primary care is ordinarily provided by family practice physicians, internists, pediatricians, or physician surrogates (physician assistants, nurse practitioners, pediatric associates, etc.). A primary care case-management program may include the provision of, or arrangements for, all available services as long as primary care services are provided as well.

A specialty physician services arrangement allows States to restrict recipients of specialty services to designated providers, even in the absence of a primary care case-management system.

For example, a State may restrict to specific clinics those recipients in need of mental health outpatient services. A primary care case-management system need not be part of this program.

B. Locality As A Central Broker (Section 1915(b)(2)).—A locality may act as a central broker in assisting individuals in selecting among competing health care plans. This provides beneficiaries more information about the range of health care options open to them.

A locality is any defined jurisdiction, e.g., district, town, city, borough, county, parish or State. A locality may utilize any agency or agent, public or private, profit or nonprofit, to act on its behalf in carrying out its central broker function.

The waiver must specify who is acting as a broker.

C. Sharing of Cost Savings (Section 1915(b)(3)).—States may share (through the provisions of additional services) with recipients cost savings resulting from the use of cost-effective medical care. Additional services include those offered by plans selected by recipients, as well as those offered expressly by a State as an inducement for recipients to participate in a primary care case-management system, a competing health care plan, or other arrangements that result in more cost-effective medical care. "Additional services" may be in the form of services not otherwise provided in the State plan, or the elimination of copayments or service limitations.

The waiver should describe the more cost-effective medical options used by recipients. The waiver should describe additional services to which the recipient is entitled. The cost of the additional services should not exceed the anticipated savings.

The State may offer inducements to eligibles to enroll although this may at first require expenditures of additional funds, provided there is an assurance of savings in the long run.

D. Restriction of Recipients to Specified Providers (Section 1915(b)(4)).—States may require recipients to obtain services only from specified providers who undertake to provide such services and meet specified reimbursement, quality, and utilization standards provided that these restrictions do not apply in emergency circumstances.

1. A State may qualify for a freedom of choice waiver under section 1915(b)(4) if:

a. Applicable State standards are consistent with access, quality, efficiency, and economic provision of covered care and services. The standards which will apply to providers must be included in the waiver submission. The following are examples of the types of standards that may be applied under a waiver:

(1) Access

(a) Providers must have sufficient capacity to provide reasonable access to quality services.

(b) Providers must agree to provide covered services to any Medicaid recipient eligible for services when prescribed by or otherwise authorized under the waiver.

(2) Utilization Controls.—The provider must agree to comply with the State plan standards regarding utilization.

(3) Quality Controls.

(a) Providers must be Medicaid qualified providers.

(b) Providers must demonstrate the ability to operate efficiently and to provide quality services on an economical basis.

(c) Providers must meet all State licensure laws and agree to [illegible]de by all pertinent State Medicaid regulations.

(d) Providers must agree to comply with the State plan standards regarding quality.

(e) Each provider shall have in effect a quality assurance program based on written policies, standards, and procedures which are in accordance with acceptable medical practices and with professional standards.

(f) Each provider shall have procedures for accepting, processing, and responding to enrollee grievances.

(4) Reimbursement.

(a) Providers must agree to accept the standards for reimbursement under the State plan or waiver. The reimbursement standards under the waiver are not necessarily restricted to those in the State plan; for example, the provider could agree to accept a negotiated amount of reimbursement.

(b) The restrictions imposed do not discriminate among classes of providers on grounds unrelated to their demonstrated effectiveness and efficiency in providing those services. Demonstrated effectiveness and efficiency refers to reducing costs or slowing the rate of increase and maximizing outputs or outcomes per unit of cost.

(c) A State restricts recipients to obtaining services only from qualified providers or practitioners that:

(i) Undertake to provide the covered care or medical services needed, and

(ii) Comply with State plan standards for reimbursement, quality, and utilization.

(d) Recipients residing at a long-term care facility are not subject to a restriction on freedom of choice based on this waiver authority unless the State arranges for reasonable and adequate recipient transfer.

2108. DOCUMENTATION OF COST EFFECTIVENESS, THE EFFECT ON ACCESS TO CARE AND QUALITY OF SERVICES, AND THE PROJECTED IMPACT

The 1981 amendments to the Act (P.L. 97-35) authorize the Secretary to waive requirements of section 1902 to implement specific programs to the extent he or she finds it to be cost-effective and efficient and not inconsistent with the purposes of title XIX (emphasis supplied). In order for the Secretary to determine that this requirement is met, regulations at 42 CFR 431.55(b) require the State in applying for a waiver to document and maintain data regarding:

(1) The cost effectiveness of the project;

(2) The effect on recipients regarding access to care and quality of services; and

(3) The projected impact of the project.

HCFA's approach in granting waivers has been to allow the State maximum flexibility in planning their waiver packages and in demonstrating cost-effectiveness and efficiency, access, and the projected program impact.

HCFA evaluates waiver requests on a State-by-State basis, bearing in mind special circumstances that may apply in each State. Rather than setting rigid standards, HCFA is requiring the States to adequately explain and demonstrate why the proposal will be cost-effective, as well as the effect of the project on recipient access to services, and the projected impact of the program. Mere assurances will not suffice.

A. Cost effectiveness.- Regulations at 42 CFR 431.55(f) define "cost effective and efficient" to mean reducing costs or slowing the rate of increase or maximizing outputs or outcomes per unit of cost. This is the test that will be used in determining whether the requirement for cost effectiveness is met under all waiver proposals. In its waiver request, the State must present sufficient documentation that reasonably supports a conclusion that this requirement is met. There is no prescribed formula or documentation list to be met. The key is that the documentation must reasonably support a conclusion that the test is met given the particular circumstances and nature of the State's waiver request.

On the one hand, the proposal must document what factors have been taken into account in estimating project costs and savings and the weight given those factors. Total costs must be shown under the waiver for program benefits, administrative costs, systems modifications, marketing incentives, and similar items. The basis for the savings under the waiver must also be documented and related to the reasons why they occur such as changes in utilization rates, number of eligible recipients, and changes in reimbursement methodologies and other factors.

These costs and savings must then be compared with costs and savings which would have been incurred in the State for like services and recipients without a waiver. Again changes that are occurring in the State that are not directly related to the waiver must be identified and the base of comparison must be appropriately adjusted for costs and savings associated with these changes. For example, changes in utilization, characteristics of the recipients, and changes in reimbursement rates or methodologies may be occurring in a State due to changes in administrative policy or State legislation regardless of the approval of a waiver.

This cost/savings comparison of factors under the waiver and factors without the waiver must be clearly enough delineated so that a case is made that operations under the waivers will in fact be cost-effective.

For example, the State may present data and reasonable estimates that under its waiver request the overall cost of the Medicaid program for the recipient population within the waiver project will be less than for the previous year (or for a comparable population), or there will be a decrease in the rate of increase of costs. The inflation rate should be considered in determining where costs decreased or rate of increase slowed. Or the State may show, based on data and reasonable estimates, that the average per capita expenditures under the waiver will not exceed the average per capita expenditures for the same services under the State plan that would have been made in the same time period had the waiver not been granted.

In some circumstances, an initial increase in costs may be acceptable as long as the proposal demonstrates how, over the term of the waiver, there will be an overall savings, or no overall cost increase.

B. The Effect on Recipients' Access to Care and Quality of Care.—A waiver program may not substantially impair access to services of adequate quality. The waiver application must assure the provision of an adequate amount of services during reasonable time periods and within reasonable geographic distance of the residence of Medicaid recipients. The waiver application must contain adequate documentation which supports a reasonable conclusion that recipient access to care and quality of care will not be substantially impaired. Access to emergency services may not be limited under waiver proposals.

C. Projected Impact of the Program.—The waiver request must document the impact of the waiver request on the Medicaid program including program costs, recipient access, quality of care, provider impact, program administration and any other relevant impact areas. Program impact must be consistent with the objectives of Medicaid and the requirements of the law and regulations, except to the extent waivers are granted pursuant to section 1915(b).

2109. SECTION 1915(b) WAIVERS—EXTENSION OF THE WAIVER

At the end of the 2-year term of the original waiver, States may request a continuation of the waiver for up to another 2-year period. States are to submit requests for the extension of the waiver through the HCFA regional offices. Requests should be submitted at least 90 days, but no earlier than 120 days, before the date the existing waiver expires, to ensure an uninterrupted waiver program.

A. Processing of Waiver Request.—A request for a two-year extension of a waiver program which does not make changes in the waiver program is processed under section 1915(d) of the Act. This section requires that the Secretary either approve or disapprove the request within 90 days of receipt of the request.

Where, however, a State proposes to modify its waiver program (i.e., make changes in the eligible population, services provided, service area or statutory sections waived) at the time it requests an extension of its initial waiver, this request will be processed as a new waiver request subject to the requirements of section 1915(f) of the Social Security Act rather than as a request for extension. For example, where a State has initially limited participation in its waiver program to AFDC and AFDC-related recipients but upon renewal wishes to expand its waiver program to other eligible groups, the request would be considered a new waiver.

Since provisions of section 1903(m) may no longer be waived, waivers of 1903(m) will expire with the term of the initial waiver. Accordingly, requests for extension of waiver programs which have been modified to eliminate waiver of 1903(m) requirements will be processed as new waiver requests, subject to the requirements of section 1915(f) of the Act.

If a State submits a renewal request after the expiration date of its waiver, the request will be processed under the time frames of section 1915(f).

B. Evaluating the Waiver Request.—For the purpose of determining whether an extension should be granted, as well as for purposes of evaluating the waiver project, HCFA must determine whether the project has met the requirements established by statute, and has indeed been cost-effective and efficient.

At this time, specific information must be presented to HCFA documenting the cost-effectiveness of the project, the effect on recipients regarding access to care and quality of services, and the impact of the program. The documentation must be sufficient to support a determination that these requirements, as defined in section 2108, were met during the approved project period and will continue to be met during the requested extension period. In addition, those States which request an extension of the waiver must also provide a rationale for extending the project. Examples of the types of specific information which may be included, dependent upon the type of waiver program which is being considered for continuation, are included below.

1. Measures of Cost-Effectiveness.—There is no prescribed formula or documentation list to be met. In dealing with cost-effectiveness, the State must present data on actual program costs during the project for the recipient population within the project and all systems, administrative, and related costs. The State should also demonstrate how the actual experience in comparison with pre-project experience, comparisons with control populations, or through other measures, shows that the project has reduced costs or slowed the rate cost increases, or maximized outputs or outcomes per unit of cost. Thus, for example, the State may provide a comparison of per capita Medicaid expenditures for the recipient population within the project against a similar Medicaid population, or may provide a comparison of costs per participating recipient prior to the waiver and during the waiver project. In addition, the State must project anticipated program costs and administrative costs for the requested continuation period and compare them with what costs would be without the waiver.

In determining cost-effectiveness, the effects of any other programmatic or legislative changes should be isolated and the costs and/or savings that were or would be achieved under the waiver or without the waiver should be appropriately adjusted.

2. Measures of Effect on Recipient.—Documentation should be provided regarding the number of recipients (annualized unduplicated) affected by the waiver. A State may also provide information on the number of recipients voluntarily and involuntarily dropping out, and the reasons. If the project affects the State's total Medicaid program, documentation should be provided which shows how the recipients have been affected as a consequence of the waiver in contrast with normal trends without the waiver.

Documentation regarding access should include such data as the number and types of providers under the waiver as contrasted with prior experience or reasonably anticipated experiences. Furthermore, such factors as travel time can be useful in assessing access. Some evidence about the quality of care also needs to be provided. This could include UR and PRO data as well as documentation of the volume and type of complaints received regarding access and quality of care and any State corrective actions.

States with primary care case-management programs may provide documentation regarding the case-management process including issues such as recipient contact with case-manager, e.g., frequency and type of contact. This should include evidence of how the use of case managers has improved program effectiveness and efficiency.

3. Impact of Program.—In supporting consistency with Medicaid goals, the State should document overall program costs. This includes increases, decreases, or no change on costs. Unanticipated administrative modifications should be noted. This may include evidence regarding changes in systems/claims processing, eligibility determinations, caseloads, and other factors (e.g., increase in hearings due to waiver-related issues).

Also useful in assessing this factor is documentation regarding provider participation. This may include increases, decreases, and complaints (e.g., litigation), and favorable reactions.

In order to assess under waivers dealing with restricted providers that there has been no discrimination among providers except on the basis of demonstrated efficiency and effectiveness, States need to provide documentation of quality, utilization, and reimbursement standards used as well as any departures from State plan standards.

Special factors must be considered in relationship to risk and non-risk prepaid health plans. The regulations governing these entities are found in 42 CFR 434.

C. Rationale for Extension.—States must provide a rationale for the extension of the waiver, along with the required documentation, to the regional office. Documentation should include projections of utilization, beneficiary population, and cost for the continuation based on actual experience. In addition, States must provide assurances that the project has not interfered with access to emergency services, and has operated in accordance with the purposes of title XIX.

D. Requests for Clarification and Additional Documentation.—In instances where the State's submittal of specific documentation does not support a finding that the waiver has satisfied the conditions for which it was approved or clarification is needed, the State will be asked to provide additional information. It should be noted, however, that requests

for additional information in this instance do not stop the 90-day period in which the Secretary must approve or disapprove the continuation request. Consequently, States should work closely with HCFA regional staff in preparing continuation requests in order to facilitate the Secretary's decision.

If HCFA is unable to make a finding, based on the information provided by the State, that the waiver project has met the statutory and regulatory requirements and has been cost-effective and efficient, HCFA will disapprove the request for a two-year continuation. HCFA may, however, in so doing, grant the State a 90-day extension of the initially approved waiver to permit the State the opportunity to more fully document that the statutory and regulatory requirements are met without jeopardizing the continuity of the waiver. At the end of the 90-day extension, HCFA must approve or disapprove any request for further extension of the waiver based on additional documentation provided by the State or a continuing need for clarification of the data.

Where a State is modifying its initial waiver and HCFA needs additional information prior to deciding whether to approve or disapprove the State's proposal, HCFA may extend the State's waiver as initially approved (except waiver of section 1903(m)) for 90 days if the waiver is about to expire. Thus, the State would have the opportunity to respond to HCFA's request for additional information without the continuity of the waiver being jeopardized. Once the State responds to the request for additional information, HCFA will either approve or disapprove the waiver as modified.

Where a State does not respond to HCFA's request for additional information by the end of the 90-day extension, the waiver will automatically terminate.

THE FOLLOWING ARE HCFA GUIDELINES FOR STATES APPLYING FOR HOME AND COMMUNITY-BASED SERVICES WAIVERS UNDER 1915(c) OF THE SOCIAL SECURITY ACT (SECTION 2176 WAIVERS)

A. Definition of Services

A.1. Do the services for which the State is requesting a waiver under this regulation consist of at least one of the following: (42 CFR 440.180(a)(1)-(7))

a. Case management services
b. Homemaker services
c. Home health
d. Personal care services
e. Adult day care services
f. Habilitation services
g. Respite care services

YES

NO

Is room and board specifically excluded?

YES

NO

A.2. Does the State define each of the services listed in A.1., for which a waiver is being requested? (42 CFR 440.180(a))

YES

NO

A.3. If the State requests a waiver to provide home and community-based services other than those listed in A.1., does the State: (42 CFR 440.180(a)(8)&(b)

a. Define and describe each of the services in detail?

YES

NO

b. Demonstrate each service is cost-effective?

YES

NO

c. Assure us that the services are necessary to avoid institutionalization?

YES

NO

d. Exclude room and board as a covered service?

YES

Definition of Services (continued)

A.4. If the State provides meals under the waiver is it clear that they do not constitute a"full nutritional regimen" (3 meals a day) (42 CFR 440.180(b))

YES

NO

A.5. Does the waiver include coverage of educational, pre-vocational or vocational services? If so, these services must be deleted and a specific assurance to that effect must be obtained.

YES

NO

A.6. If the waiver request includes respite care, does the State describe the limitations on the amount of care which may be provided to a recipient each year?

YES

NO

B. Content of Waiver Requests

B.1. If the State does not intend to offer these services to and all individuals who would otherwise likely require institutionalization does the State include waiver requests of: section 1902(a)(1) (statewideness)?

YES

NO

Section 1902(a)(10) (comparability)?

YES

NO

Both?

YES

NO

(42 CFR 441.301(a)(2))

B.2. If the State requests a waiver of section 1902(a)(1), does it indicate in which political subdivisions of the State waiver services will be provided?

YES

NO

B.3. If the State intends not to offer home community-based services to beneficiaries on the basis that it can reasonably expect that the services would cost more than institutional services, does the State request an appropriate waiver and explain how it will make and implement such determinations? (42 CFR 441.301(a)(3))

YES

NO

C. Waiver Request Requirement

C.1. Does the waiver request describe who is eligible to receive the waivered services? (42 CFR 441.301(b)(ii)(3))

YES

NO

C.2. Does the request provide an explanation of how the agency will apply the applicable provisions regarding the post-eligibility treatment of income and resources of those receiving home and community-based services who are eligible under the special income level. (42 CFR 441.303(e))

YES

NO

C.3. Does it also state the services will only be furnished to those eligible beneficiaries who, but for this provision, would require the level of care provided in an ICF or SNF?* (42 CFR 441.301(b)(1)(ii))

YES

NO

* "The level of care provided in an ICF" includes the level of care furnished to beneficiaries in ICFs for the mentally retarded (ICF/MR) (42 CFR 440.150(c)).

C. Waiver Request Requirements (continued)

C.4. If the request is targeted to the mentally ill, is it clear that services will not be be provided to individuals in the 22-64 age group who would otherwise have been institutionalized in an institution for mental diseases (IMD)?

YES

NO - If no, a specific assurance to that effect must be obtained.

C.5. Does the request indicate how the statutory requirement for an individual written plan of care will be met? (42 CFR 441.301(b)(1)(i))

YES

NO

C.6. Does the waiver indicate that the plan of care will include the medical and other services to be given, their frequency and the type of provider to furnish them?

YES

NO

C. Waiver Request Requirements (continued)

C.7. Does the waiver request include a description of the qualifications of the individuals who will be responsible for developing the individual plan of care? (42 CFR 441.301(b)(2))

YES

NO

C.8. Does the waiver request specifically provide that the written plan of care is subject to approval by the Medicaid agency? (42 CFR 441.301(b)(1)(i))

YES

NO

C.9. Does the waiver request specifically indicate that the services will not be provided to recipients who are inpatients of a hospital, SNF, ICF or ICF/MR? (42 CFR 441.301(b)(1)(ii))

YES

NO

D. State Assurances - Safeguards

D.1. Does the request state precisely "The State of _____ assures HCFA that necessary safeguards have been taken to protect the health and welfare of the recipients of the services. These safeguards must include adequate standards for all types of providers that provide services under the waiver." (42 CFR 441.302(a)(1))

YES

NO

D.2. Has the State submitted standards for each type of provider of waiver services (or, if a renewal, copies of those not included in the original request)?

YES

NO

D.3. Are the standards adequate?

YES

NO

94

D. State Assurances - Safeguards (continued)

D.4. Does the State specify what the necessary safeguards are, define them or specify how they will be developed and implemented and explain how they satisfy the statute?

YES

NO

D.5. If the State has licensure or certification requirements for any services (or for the individuals who furnish these services) provided under the waiver, does the State specifically assure HCFA that the standards in the licensure or certification requirements will be met?
(42 CFR 441.302(a)(2))

YES

NO

D.6. Does the request state precisely: "The State of _____ assures HCFA that all facilities covered by section 1616(e) of the Social Security Act, in which home and community-based services will be provided, are in compliance with applicable State standards that meet the requirements of 45 CFR Part 1397 for board and care facilities."
(42 CFR 441.302(a)(3))

YES

NO

D. State Assurances - Safeguards (continued)

D.7. Has the State also submitted to HCFA a copy of the standards established by the State for facilities that are covered by section 1616(e) of the Social Security Act?
(42 CFR 441.303(a))

YES

NO

D.8. Does the request state precisely: "The State of _____ assures HCFA that the agency will assure financial accountability for funds expended for home and community-based services, provide for an independent audit of its waiver program (except as HCFA may otherwise specify for particular waivers), and it will maintain and make available to HHS, the Comptroller General, or other designees, appropriate financial records documenting the cost of services provided under the waiver, including reports of any independent audits conducted."
(42 CFR 441.302(b))

YES

NO

D.9. Does the State give us a description of the records and information that will be maintained by the agency and by providers of waiver services to support financial accountability, inform us how it will meet the requirement, and explain how it will assure that there is an audit trail for all State and Federal funds?
(42 CFR 441.303(b))

YES

NO

E. State Assurances - Individual Assessments

E.1. Does the request state precisely: "The State of _____ assures HCFA that the agency will provide for an evaluation (and periodic revaluations) of the need for the level of care provided in an SNF, ICF, or ICF/MR, as defined by 42 CFR 440.40 and 440.150 respectively, when there is a reasonable indication that individuals might need such services in the near future but for the availability of home and community-based services." (42 CFR 441.302(c))

YES

NO

E.2. Does the request include a description of:

a. The agency's procedure for evaluating and reevaluating the recipients need for an ICF or SNF level of care?

YES

NO

b. Who will perform the evaluations and reevaluations?

YES

NO

(42 CFR 441.303(c)(1))

c. Does the State provide a copy of the written assessment instrument that will be used?

YES

NO

97

E. State Assurances - Individual Assessments (continued)

E.3. Does the request indicate when the initial evaluation will be performed?

YES

NO

Does the request specify how often reevaluations will be performed?

YES

NO

E.4. For those diverted from institutional care, has the State provided a more detailed description of their evaluation and screening procedures for recipients to assure that waiver services will be limited to those who would otherwise receive the level of care provided in an SNF, ICF, or ICF/MR? (42 CFR 441.303(f)(4))

YES

NO

E.5. Does the waiver request describe the agency's procedure to ensure the maintenance of written documentation on all evaluations and reevaluations and the procedure to ensure reevaluations of need at regular intervals? This should include an indication of the length of time for which these records will be maintained. (42 CFR 441.303(c)(3))

YES

NO

F. State Assurances - Informing Beneficiaries of Choice

F.1. Does the request state precisely: "The State of _____ assures HCFA that when a recipient is determined to be likely to require the level of care provided in an SNF, ICF, or ICF/MR the recipient of his or her legal representative will be (1) informed of any feasible alternatives, available under the waiver and (2) given the choice of either institutional or home and community-based services." (42 CFR 441.302(d))

YES

NO

F.2. Does the request include a description of the agency's procedure for informing eligible recipients of the feasible alternatives available under the waiver and allowing recipients to choose either institutional services or home and community-based services? (42 CFR 441.303(d))

YES

NO

F.3. Does the waiver request provide an opportunity for a fair hearing under 42 CFR, Part 431, Subpart E, to beneficiaries who are not given the choice of home or community-based services as an alternative to SNF or ICF services or who are denied the service of their choice?

YES

NO

99

G. State Assurances - Average Per Capita Expenditure

G.1. Does the State in its waiver request specifically assure HCFA that the average per capita fiscal year expenditure under the waiver will not exceed the average per capita expenditures for the level of care provided in a SNF, ICF or ICF/MR under the State plan that would have been made had the waiver not been granted?
(42 CFR 441.302(e)(1))

YES

NO

G.2. Does the request state precisely: "The State of _____ assures HCFA that the agency's actual total expenditures for home and community-based and other Medicaid services provided to individuals under the waiver will not, for any year of the waiver period, exceed the amount that would be incurred by Medicaid for these individuals in an SNF, ICF, or ICF/MR in the absence of a waiver."
(42 CFR 441.302(e)(3))

YES

NO

G.3. Do these estimates cover each fiscal year during the 3-year term of the waiver and are they reasonable, based on statistically sound and valid procedures, and verifiable?
(42 CFR 441.302(e))

YES

NO

100

G. State Assurances - Average Per Capita Expenditure (continued)

G.4. Did the State develop its estimated average per capita expenditures by using the new formula specified in 42 CFR 441.303(f)(1)?

YES

NO

G.5. Has the State developed estimates of the costs and utilization for each type of waiver service and an estimate of the total population that would likely receive these services? (42 CFR 441.303(f))

YES

NO

G.6. Are the individual components of the per capita expenditure formula reasonable, documented and fully explained?

YES

NO

101

G. State Assurances - Average Per Capita Expenditure (continued)

G.7. Did the State provide the number of actual and projected beds in Medicaid certified SNFs, ICFs and ICF/MRs by type?
(42 CFR 441.303(f))
NOTE: Data need only be provided for level(s) of care targeted in the request.

YES

NO

G.8. Did the State provide evidence of the need for additional bed capacity in the absence of the waiver (if applicable) such as certificates of need and other documentation that beds would actually be available for those to enter the waiver?
(42 CFR 441.303(f))

YES

NO

G.9. Did the State provide occupancy rates by type of certified facility, whether there are excess beds, and if so, how many?
(42 CFR 441.303(f))

YES

NO

G. State Assurances - Average Per Capita Expenditure (continued)

G.10. Did the State provide the number of persons on waiting lists for each type of institution and the length of time people must wait for admission?
(42 CFR 441.303(f))

YES

NO

G.11. Did the State provide the number of individuals being deinstitutionalized and where they will come from (e.g., SNF)?
(42 CFR 441.303(f)(4))

YES

NO

G.12. Did the State provide the number of individuals being diverted from institutional care, where they will come from, how many will come from each location (e.g., SNF waiting list, ICF waiting list etc.)?
(42 CFR 441.303(f)(4))

YES

NO

103

G. State Assurances - Average Per Capita Expenditure (continued)

G.13. In developing the estimates of utilization necessary to complete the above computations, does the State use actual data on nursing home cost and utilization of community-based services for the most recent year before the waiver takes effect i.e., are the estimates and documentation supported by data reported on the HCFA 2082s and 371s (if applicable)? (These figures would be adjusted by the State to reflect anticipated growth resulting from change in the supply of nursing home beds, availability of community-based services and inflation.)

YES

NO

G.14. Does the request state precisely: "The State of _____ assures HCFA that the agency's actual total expenditures for home and community-based services under the waiver and its claim for FFP in expenditures for services will not exceed the agency's approved estimates for these services, expressed as the product of (C x D) in the supporting documentation required under 42 CFR 441.303(f) for each year of the waiver period." (42 CFR 441.302(e)(2))

YES

NO

104

H. State Assurances - Annual Report on Impact

H.1. Did the State specifically assure HCFA that it would provide HCFA annually with information on the impact of the waiver on the type, amount and cost of services provided under the State plan and on the health and welfare of recipients? (42 CFR 441.302(f))

YES

NO

H.2. Does the State specifically assure HCFA that the data will be consistent with the data collection plan designed by HCFA? (42 CFR 441.302(f))

YES

NO

105

Provisions of Final Regulations Applicable to Specified Waivers

I. This item applies to initial waiver and renewal requests received after April 12, 1985.

Has the State provided for an independent assessment of its waiver (except as HCFA may otherwise specify for particular waivers) that evaluates the quality of care provided, access to care and cost-effectiveness? (42 CFR 441.303(g))

YES

NO

2. If it is a renewal request, has the State submitted the results of the assessment that covers at least the first 24 months of the waiver (42 CFR 441.303(g)).

YES

NO

J. This item applies to initial requests received after April 12, 1985.

Is the request limited to one of the following target groups or any subgroup thereof that the State may define? (42 CFR 441.301(b)):

(i) Aged or disabled, or both

(ii) Mentally retarded or developmentally disabled or both

(iii) Mentally ill

§ 440.180 Home or community-based services.

"Home or community-based services" means services, not otherwise furnished under the State's Medicaid plan, that are furnished under a waiver granted under the provisions of Part 441, Subpart G of this subchapter. Except as provided in § 441.310 the services may consist of any of the following services as defined by the agency that meet the standards specified in § 441.302(a):

(a) Case management services;
(b) Homemaker services;
(c) Home health aide services;
(d) Personal care services;
(e) Adult day health services;
(f) Habilitation services;
(g) Respite care services;
(h) Other services requested by the Medicaid agency and approved by HCFA as cost-effective.

[50 FR 10026, Mar. 13, 1985]

Subpart B—Requirements and Limits Applicable to All Services

§ 440.200 Basis, purpose, and scope.

(a) This subpart implements—

(1) Section 1902(a)(10), regarding comparability of services for groups of recipients, and the amount, duration, and scope of services described in section 1905(a) of the Act that the State plan must provide for recipients;

(2) Section 1902(a)(22)(D), which provides for standards and methods to assure quality of services;

(3) Section 1907 on observance of religious beliefs; and

(4) Section 1915 on exceptions to section 1902(a)(10) and waivers of other requirements of section 1902 of the Act.

(b) The requirements and limits of this subpart apply for all services defined in Subpart A of this part.

[46 FR 48528, Oct. 1, 1981]

§ 440.210 Required services for the categorically needy.

A State plan must specify that, as a minimum, categorically needy recipients are provided the services as specified in §§ 440.10 through 440.50, 440.70, and (to the extent nurse-midwives are authorized to practice under State law or regulation) 440.165.

[47 FR 21050, May 17, 1982]

§ 440.220 Required services for the medically needy.

A State plan that includes the medically needy must specify that the medically needy are provided, as a minimum, the following services:

(a) Prenatal care and delivery services for pregnant women.

(b) Ambulatory services, as defined in the State plan, for—

(1) Individuals under age 18; and

(2) Individuals entitled to institutional services.

(c) Home health services (§ 440.70) to any individual entitled to skilled nursing facility services.

(d) If the State plan includes services in an institution for mental diseases (§ 440.140 or § 440.160) or in an intermediate care facility for the mentally retarded (§ 440.150(c)) for any group of medically needy, either of the following sets of services to each of the medically needy groups:

(1) The services contained in §§ 440.10 through 440.50 and (to the extent nurse-midwives are authorized to practice under State law or regulation) 440.165; or

(2) The services contained in any seven of the sections in §§ 440.10 through 440.165.

[46 FR 47992, Sept. 30, 1981; 46 FR 54745, Nov. 4, 1981, as amended at 47 FR 21050, May 17, 1982]

§ 440.230 Sufficiency of amount, duration, and scope.

(a) The plan must specify the amount, duration, and scope of each service that it provides for—

(1) The categorically needy; and

(2) Each covered group of medically needy.

Subpart G—Home and Community-Based Services: Waiver Requirements

SOURCE: 46 FR 48541, Oct. 1, 1981, unless otherwise noted.

§ 441.300 Basis and purpose.

Section 1915(c) of the Act permits States to offer, under a waiver of statutory requirements, an array of home and community-based services that an individual needs to avoid institutionalization. Those services are defined in § 440.180 of this subchapter. This subpart describes what the Medicaid agency must do to obtain a waiver.

§ 441.301 Contents of request for a waiver.

(a) A request for a waiver under this section must consist of—

(1) The assurances required by § 441.302 and the supporting documentation required by § 441.303;

(2) When applicable, requests for waivers of the requirements of section 1902(a) (1) or (10) of the Act; and

(3) A statement as to whether the agency will refuse to offer home or community-based services to any recipient because it can reasonably expect that the cost of the home or community-based services furnished to that recipient would exceed the cost of the level of care provided in an SNF or ICF (or ICF/MR if applicable).

(b) If the agency furnishes home and community-based services, as defined in § 440.180 of this subchapter, under a waiver granted under this subpart, the waiver request must—

(1) Provide that the services are furnished—

(i) Under a written plan of care subject to approval by the Medicaid agency;

(ii) Only to recipients who are not inpatients of a hospital, SNF, ICF, or ICF/MR, and who the agency determines would require the level of care provided in an SNF or ICF (or ICF/MR, if applicable) under Medicaid (as defined in §§ 440.40 and 440.150) if not furnished these services;

(2) Describe the qualifications of the individual or individuals who will be responsible for developing the individual plan of care;

(3) Describe the group or groups of individuals to whom the services will be offered;

(4) Describe the services to be furnished;

(5) Provide that the documentation requirements regarding individual evaluation, specified in § 441.303(c), will be met; and

(6) Be limited to one of the following target groups or any subgroup thereof that the State may define:

(i) Aged or disabled, or both.

(ii) Mentally retarded or developmentally disabled, or both.

(iii) Mentally ill.

[46 FR 48541, Oct. 1, 1981, as amended at 50 FR 10026, Mar. 13, 1985]

§ 441.302 State assurances.

HCFA will not grant a waiver under this subpart and may terminate a waiver unless the Medicaid agency provides the following satisfactory assurances to HCFA:

(a) *Health and Welfare*—Assurance that necessary safeguards have been taken to protect the health and welfare of the recipients of the services. Those safeguards must include—

(1) Adequate standards for all types of providers that provide services under the waiver;

(2) Assurance that the standards of any State licensure or certification requirements are met for services or for individuals furnishing services that are provided under the waiver; and

(3) Assurance that all facilities covered by section 1616(e) of the Act, in which home and community-based services will be provided, are in compliance with applicable State standards that meet the requirements of 45 CFR Part 1397 for board and care facilities.

(b) *Financial accountability.*—The agency will assure financial accountability for funds expended for home and community-based services, provide for an independent audit of its waiver program (except as HCFA may otherwise specify for particular waivers), and it will maintain and make available to HHS, the Comptroller General, or other designees, appropriate financial records documenting the cost of services provided under the waiver, including reports of any independent audits conducted.

(c) *Evaluation of need.*—Assurance that the agency will provide for an evaluation (and periodic reevaluations) of the need for the level of care provided in an SNF, ICF, or ICF/MR, as defined by §§ 440.40 and 440.150, respectively, when there is a reasonable indication that individuals might need such services in the near future but for the availability of home and community-based services.

(d) *Alternatives*—Assurance that when a recipient is determined to be likely to require the level of care provided in an SNF, ICF, or ICF/MR, the recipient or his or her legal representative will be—

(1) Informed of any feasible alternatives available under the waiver; and

(2) Given the choice of either institutional or home and community-based services.

(e) *Expenditures*—Assurance that—(1) The average per capita fiscal year expenditures under the waiver will not exceed the average per capita expenditures for the level of care provided in an SNF, ICF, or ICF/MR under the State plan that would have been made in that fiscal year had the waiver not been granted. (i) These expenditures must be reasonably estimated by the agency; and (ii) The estimates must be annualized and must cover each year of the waiver period.

(2) The agency's actual total expenditures for home and community-based services under the waiver and its claim for FFP in expenditures for the services will not exceed the agency's approved estimates for these services, expressed as the product of (C×D) in the supporting documentation required under § 441.303(f), for each year of the waiver period.

(3) The agency's actual total expenditures for home and community-based and other Medicaid services provided to individuals under the waiver will not, in any year of the waiver period, exceed the amount that would be incurred by Medicaid for these individuals in an SNF, ICF, or ICF/MR, in the absence of a waiver.

(f) *Reporting.*—Assurance that annually, the agency will provide HCFA with information on the waiver's impact. The information must be consistent with a data collection plan designed by HCFA and must address the waiver's impact on—

(1) The type, amount, and cost of services provided under the State plan; and

(2) The health and welfare of recipients.

[50 FR 10026, Mar. 13, 1985]

§ 441.303 Supporting documentation required.

The agency must furnish HCFA with sufficient information to support the assurances required by § 441.302. Except as HCFA may otherwise specify for particular waivers, the information must consist of the following, at a minimum:

(a) A description of the safeguards necessary to protect the health and welfare of recipients. This information must include a copy of the standards established by the State for facilities that are covered by section 1616(e) of the Act.

(b) A description of the records and information that will be maintained to support financial accountability.

(c) A description of the agency's plan for the evaluation and reevaluation of recipients, including—(1) A description of who will make these evaluations and how they will be made; (2) A copy of the evaluation instrument to be used; (3) The agency's procedure to ensure the maintenance of written documentation on all evaluations and reevaluations; and (4) The agency's procedure to ensure reevaluations of need at regular intervals.

(d) A description of the agency's plan for informing eligible recipients of the feasible alternatives available under the waiver and allowing recipi-

ents to choose either institutional services or home and community-based services.

(e) An explanation of how the agency will apply the applicable provisions regarding the post-eligibility treatment of income and resources of those individuals receiving home and community-based services who are eligible under a special income level (included in § 435.217 of this chapter).

(f) An explanation with supporting documentation satisfactory to HCFA of how the agency estimated the per capita expenditures for services. This information must include but is not limited to the estimated utilization rates and costs for services included in the plan, the number of actual and projected beds in Medicaid certified SNFs, ICFs, and ICF/MRs by type, and evidence of the need for additional bed capacity in the absence of the waiver.

(1) The annual average per capita expenditure estimate of the cost of home and community-based and other Medicaid services under the waiver must not exceed the annual average per capita expenditures of the cost of services in the absence of a waiver. The estimates are to be based on the following equation:

$$\frac{(A\times B)+(A'\times B')+(C\times D)+(C'\times D')+(H\times I)}{F+H} \leq \frac{(F\times G)+(H\times I)+(F'\times G')}{F+H}$$

where:

A = the estimated annual number of beneficiaries who would receive the level of care provided in an SNF, ICF, or ICF/MR with the waiver.

B = the estimated annual Medicaid expenditure for SNF, ICF, or ICF/MR care per eligible Medicaid user with the waiver.

C = the estimated annual number of beneficiaries who would receive home and community-based services under the waiver.

D = the estimated annual Medicaid expenditure for home and community-based services per eligible Medicaid user.

F = the estimated annual number of beneficiaries who would likely receive the level of care provided in an SNF, ICF, or ICF/MR in the absence of the waiver.

G = the estimated annual Medicaid expenditure per eligible Medicaid user of such institutional care in the absence of the waiver.

H = the estimated annual number of beneficiaries who would receive any of the noninstitutional, long-term care services otherwise provided under the State plan as an alternative to institutional care.

I = the estimated annual Medicaid expenditure per eligible Medicaid user of the noninstitutional services referred to in H.

The symbol "≤" is intended to mean that the result of the left side of the equation must be less than or equal to the result of the right side of the equation.

A' = the estimated annual number of beneficiaries referred to in A who would receive any of the acute care services otherwise provided under the State plan.

B' = the estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in A'.

C' = the estimated annual number of beneficiaries referred to in C who would receive any of the acute care services otherwise provided under the State plan.

D' = the estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in C'.

F' = the estimated annual number of beneficiaries referred to in F who would receive any of the acute care services otherwise provided under the State plan.

G' = the estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in F'.

(2) For purposes of the equation, acute care services means all services otherwise provided under the State plan that are neither SNF, ICF, or ICF/MR services, nor the noninstitutional, long-term care services referred to in H.

(3) Data on the estimated annual number of beneficiaries and expenditures for those who would otherwise receive an SNF, ICF, or ICF/MR level of care is required for all three types of institutions only if the waiver request provides that each of these groups will be offered home and com-

munity-based services. For example, if the request does not include persons who would otherwise receive an ICF/MR level of care, the State is not required to furnish data on that group.

(4) The data must show the estimated annual number of beneficiaries who will be deinstitutionalized from certified SNFs, ICFs and ICF/MRs because they would receive home and community-based services under the waiver, and the estimated annual number of beneficiaries whose admission to such institutions would be diverted or deflected because of the waiver services. For the latter group, the State's evaluation process required by § 441.303(c) must provide for a more detailed description of their evaluation and screening procedures for recipients to assure that waiver services will be limited to persons who would otherwise receive the level of care provided in an SNF, ICF, or ICF/MR.

(g) Except as HCFA may otherwise specify for particular waivers, the agency must provide for an independent assessment of its waiver that evaluates the quality of care provided, access to care, and cost-effectiveness. The results of the assessment must be submitted to HCFA at least 90 days prior to the third anniversary of the approved waiver period and cover at least the first 24 months of the waiver.

[46 FR 48552, Oct. 1, 1981, as amended at 50 FR 10027, Mar. 13, 1985; 50 FR 25080, June 17, 1985]

§ 441.304 Duration of a waiver.

(a) The effective date for a waiver of Medicaid requirements to provide home and community-based services approved under this subpart is established by HCFA prospectively on or after the date of approval and after consultation with the State agency.

The waiver continues for a three-year period from the effective date. If the agency requests it, the waiver may be extended for additional three-year periods, if HCFA's review of the prior three-year period shows that the assurances required by § 441.302 of this subpart were met.

(b) HCFA will determine whether a request for extension of an existing waiver is actually an extension request or a request for a new waiver.

(1) Generally, if a State's extension request proposes a change in services provided, eligible population, service area, or statutory sections waived, HCFA will consider it a new waiver request.

(2) If a State submits an extension request that would add a new group to the existing group of beneficiaries covered under the waiver, HCFA will consider it to be two requests; one as an extension request for the existing group, and the other as a new waiver request for the new group.

(c) HCFA *may* grant a State an extension of its existing waiver for up to 90 days to permit the State to document more fully the satisfaction of statutory and regulatory requirements needed to approve a new waiver request. HCFA will consider this option when it requests additional information on a new waiver request submitted by a State to extend its existing waiver or when HCFA disapproves a State's request for extension.

(d) If HCFA finds that an agency is not meeting any of the requirements for a waiver contained in this subpart, the agency will be given a notice of HCFA's findings and an opportunity for a hearing to rebut the findings. If HCFA determines that the agency is not in compliance with this subpart after the notice and any hearing, HCFA may terminate the waiver. For example:

(1) If HCFA finds that the agency's actual total expenditures for home and community-based services under the waiver exceed the agency's approved estimates for these services, expressed as the product of (C × D) in the supporting documentation required under § 441.303(f), for any year of the waiver period, the waiver may be terminated; or

(2) The waiver may be terminated if HCFA finds that the agency's actual total expenditures for home and community-based and other Medicaid services provided to individuals under the waiver exceed, for any year of the waiver period, the amount that would be incurred by Medicaid for these individuals in an SNF, ICF, or ICF/MR, in the absence of a waiver.

[50 FR 10028, Mar. 13, 1985; 50 FR 25080, June 17, 1985]

§ 441.305 Notification of a waiver termination.

(a) If a State chooses to terminate its waiver before the three-year period is up, it must notify HCFA in writing 30 days before terminating services to recipients.

(b) If HCFA or the State terminates the waiver, the State must notify recipients of services under the waiver in accordance with § 431.210 of this subchapter and notify them 30 days before terminating services.

§ 441.306 Hearings procedures for waiver terminations.

The procedures specified at 45 CFR Part 213 are applicable to State requests for hearings on terminations.

[50 FR 10028, Mar. 13, 1985]

§ 441.310 Limits on Federal financial participation (FFP).

(a) FFP for home and community-based services listed in § 440.180 of this chapter is not available in expenditures for—

(1) Services provided in a facility subject to the health and welfare requirements described in § 441.302(a) during any period in which the facility is found not to be in compliance with the applicable State standards described in that section;

(2) Home and community-based services that exceed the agency's approved estimated total expenditures for these services, expressed as the product of (C × D) in the supporting documentation required under § 441.303(f) for each year of the waiver period; and

(3) The cost of room and board except when provided as part of respite care in a facility approved by the State that is not a private residence. For purposes of this provision, "board" means three meals a day or any other full nutritional regimen and does not include meals provided as part of a program of adult day health services.

(b) On or after June 11, 1985, the limits specified in paragraphs (a)(1) and (a)(2) of this section are applicable to all existing and future waiver programs under this part.

[50 FR 10028, Mar. 13, 1985]

Mr. WAXMAN. You also suggested Medicaid paid $50 million in Federal dollars for AIDS care in 1985 and will pay $100 million for AIDS care in 1986. What are the sources for those numbers?

Mr. ELMER SMITH. The sources for those numbers are similar, that is, they are based on published studies; but they are also based on conversations that our actuaries have had with people in the community that are providing the material, the services themselves. The 40-percent figure and the cost figures are both derived from those same types of evidence.

Mr. WAXMAN. Could you again provide for the record the backup for that estimate?

Mr. ELMER SMITH. I would be glad to. [See p. 70.]

Mr. WAXMAN. At our last hearing on AIDS, you testified along with Dr. Ann Hardy of the Centers for Disease Control, who spoke about her study of AIDS costs. At that hearing she testified that by her study AIDS care, including some patients from San Francisco, costs an average of $147,000 per patient.

How can you say that Medicaid is paying for 40 percent and yet paid only $50 million last year; 40 percent of Dr. Hardy's total for just patients diagnosed through 1984 is almost $600 million. Even if the Federal share is just half of that, then the number is $300 million, six times your estimate?

Using the CDC estimate, 40 percent of the projected costs for patients diagnosed in 1986 alone would equal $1 billion, and the Federal share would be at least $500,000, five times your estimate.

How do you reconcile those numbers?

Mr. ELMER SMITH. Well, there are about six different factors which account for the difference between these sets of numbers, Mr. Chairman.

One is Ann Hardy's figures, of course, represent for the first 10,000 AIDS patients the costs over the lifetime of those patients. Many patients do not come on to the Medicaid roles until late in the status of the disease. They either have been working, they have employer-based group insurance or their own private health insurance, which meets part of the costs; or they have their own personal resources. So, we start off by talking about the Medicaid Program, which comes in at a later stage in the progress of the disease, usually after people are no longer able to work or don't have employer-based coverage.

Mr. WAXMAN. But that doesn't really add up if you say that 40 percent of AIDS patients are receiving Medicaid—oh, I see; 40 percent of the patients——

Mr. ELMER SMITH. Are receiving——

Mr. WAXMAN [continuing]. Not 40 percent of the costs from AIDS care——

Mr. ELMER SMITH. Right.

Mr. WAXMAN [continuing]. Comes from Medi——

Mr. ELMER SMITH. Right.

Mr. WAXMAN. I see.

Mr. ELMER SMITH. There are a number of other factors. We know that Medicaid reimbursement rates are low in many States, so that they are not paying what might otherwise be charged. We know that, for example, we are not covering any condition such as ARC unless the people who have ARC have such a combination of dis-

abilities that they qualify as disabled under the Social Security Administration definition.

I would be glad to include that as a part of my statement for the record indicating what the factors are that explain the differences between these two sets of estimates.

Mr. WAXMAN. Fine, thank you. We would appreciate receiving that.

[The information requested follows:]

This report explains what factors contribute to the differences between the CDC estimate and the HCFA estimate.

The differences between the CDC estimate and the HCFA estimate of the cost of AIDS arise for the following reasons:

1) CDC has estimated the cost from diagnosis to death (392 days by their estimate) while our costs are for a given fiscal year.

2) CDC has estimated that an AIDS victim will spend 168 days in a hospital in the 392 days while we estimated 90 days in a year.

3) CDC has estimated that the average cost per hospital day was $878 while we estimated that it was $825 and $875 in FYs 1985 and 1986 respectively, which is just about the same. However, we estimated that Medicaid reimbursement levels are about 57% of charges and that the Federal share was 51.5%.

4) The CDC estimate was based on the first 10,000 cases while we estimated the average number of AIDS victims alive during FY 1985 and 1986 (using data supplied to us by CDC). We then estimated that 40% of that total would be eligible for Medicaid.

The above information is presented in the following table after which there is a discussion of the reasoning behind our estimates.

Period	Hospital days	Cost/day	Cost/ person	Number of people	Rounded Cost in $millions
CDC estimate					
392 days	168	878	147500	10000	1475
HCFA estimates					
Total, National Costs					
85 365 days	90	825	74250	6204 1/	450
86 365 days	90	875	78750	10682 1/	850
Medicaid State and Federal					
85 365 days	90	476 2/	42840	2482 3/	100
86 365 days	90	501 2/	45090	4273 3/	200
Medicaid Federal share					
85 365 days	90	245 4/	22050	2482	50
86 365 days	90	256 4/	23220	4273	100

1/ Average number of person-years.
2/ Medicaid reimbursement levels at roughly 57 percent of charges, based on State-by-State reimbursement levels weighted for the geographic distribution of AIDS patients.
3/ Person-years of people with AIDS who are Medicaid eligible.
4/ Federal share of Medicaid expenditures for AIDS patients weighted for geographical distribution of AIDS patients.

It is fairly clear from the table and the discussion preceding it that the main difference between the two estimates is item 2), the estimate of the number of days of hospitalization. The other differences arise from differences in what was being estimated. The sources for all our estimates are discussed in detail in the insert included on page 59 of the paper, "Preliminary Estimate of the Impact of AIDS on the Medicaid Program". Because of the critical nature of item 2), it is discussed again with some additions below.

In developing the estimates, HCFA actuaries examined the CDC estimate of $147,500 for the costs of in-patient hospitalization for the first 10,000 AIDS patients from diagnoses to death. This estimate was derived in large measure from a letter to the New England Journal of Medicine by staff of the New York City Department of Health based on the last 3 months of reported care for the first 1410 cases of AIDS in New York City including those who had died. These data are for a period ending in 1983. New York City costs for inpatient hospitalization were initially at the high end of the range for the country. In addition, the average number of inpatient days of hospitalization in New York City has declined significantly since the data were developed which formed the basis of the letter to the New England Journal and the CDC estimates.

At the other end of the range of estimates is the experience in the city of San Francisco which experiences relatively low inpatient hospital utilization because of the emphasis on community-based health and social services.

In order to develop a national average cost, neither end of the range seemed useful for estimating purposes. We examined a point prevalence study conducted in the last half of 1984 in New York State concerning up-State and down-State utilization of inpatient hospital services. This information suggests that, taking into account areas heavily impacted by new cases of AIDS and combining this with areas where AIDS cases have been treated for some years, AIDS patients will be treated on an inpatient hospital basis about 24 percent of the time in a year or 90 days.

This utilization should decline in the future as more emphasis is placed on community-based services. However, until there is more experience with these changing patterns, projections cannot be made beyond fiscal year 1986.

Mr. WAXMAN. Whatever numbers you use, CDC's or those in your testimony, it is clear that the cost of AIDS as a part of the Medicaid Program is going up. If Dr. Hardy's estimate is correct, in 1987 States would have perhaps $1 billion increase in their Medicaid costs because of AIDS. But the administration has proposed to put a cap on the Medicaid Program and to cut $1.3 billion.

What do you propose that States do to save $1.3 billion while their costs go up perhaps a billion, a net loss of $2.3 billion?

Mr. ELMER SMITH. As I indicated, we estimate that the costs to the Medicaid Program are nowhere near the numbers that Dr. Hardy indicated in her testimony, No. 1.

No. 2, under the Medicaid cap proposal there are at least three elements, I think, which will provide some degree of relief. That is, the cap will increase by the medical component of the price index, the Consumer Price Index, so that there will be some relief for States under that factor. In addition, there will be a $300 million hardship pool which will be distributed among States which exceed 108 percent of their Federal expenditures cap despite efforts to control program costs.

In addition, although all the details have not yet been worked out, there will be proposals made as a part of that Administration initiative to allow greater flexibility in terms of the coverage of services and the kinds of reimbursements that are made.

Mr. WAXMAN. Have you built the CDC's prediction of the epidemic curve into any of your projections of Medicaid or Medicare costs?

Mr. ELMER SMITH. Our projections, which were developed independently, are based on CDC data and are consistent with CDC estimates of a doubling of AIDS cases every 12 months.

Even the Public Health Service and the CDC cannot speak confidently too far in the future. In fact, there is a conference which is being organized in June specifically on the subject of planning for AIDS patients and planning all of the aspects of public health and education and so forth that will have to be done between now and 1991. Part of that is a recognition that none of us have a lot of firm data that we can use to make even short-term projections over a period of 5 years.

Mr. WAXMAN. Although, if our projections are on the low side, the States are going to be socked with having to carry the extra burden that those costs will bring under the Medicaid Program, should there be a cap.

Mr. ELMER SMITH. Correct, and vice versa.

Mr. WAXMAN. And how would it be vice versa?

Mr. ELMER SMITH. The States will benefit if the estimates and the extrapolations are on the high side.

Mr. WAXMAN. How would the States benefit if the——

Mr. ELMER SMITH. They will not incur as much in the way of expenditures as would otherwise be indicated by these extrapolations.

Mr. WAXMAN. But Medicaid reimburses what in fact is paid——

Mr. ELMER SMITH. That's correct.

Mr. WAXMAN [continuing]. So estimates don't make too much difference except if we then put a ceiling on the Federal share. The States certainly are going to have an increase in their Medicaid

costs as a result of AIDS. The only question is how much more of an increase they may have.

Mr. ELMER SMITH. That's correct.

Mr. WAXMAN. I have a lot of other questions, but I want to call on my colleagues to let them ask some questions; and then we will return for a second round.

Mr. Dannemeyer.

Mr. DANNEMEYER. Mr. Chairman, my first question relates to you.

Mr. WAXMAN. Of these witnesses?

Mr. DANNEMEYER. No. I just want to have you give me a response, if you would. Last fall I introduced H.R. 3646 and H.R. 3647, bills that have been assigned to this subcommittee. On December 17 I wrote a letter requesting a hearing on each of them.

What is the progress of getting a hearing on this?

Mr. WAXMAN. I am not going to answer those questions. We are having a hearing right now on an important part of the AIDS problems. These witnesses are here giving of their time to answer our questions. So, if you have questions of them, why don't you ask them questions.

Mr. DANNEMEYER. Mr. Kelso, you're a spokesman for the Public Health Service, aren't you.

Mr. KELSO. I am a spokesman for the Health Resources Services Administration and the PHS to the extent I can.

Mr. DANNEMEYER. Last fall I wrote a letter to the Public Health Service asking it to take action to protect the integrity of the blood supply of the country. I am happy to say that the American Red Cross has fully implemented that request. They did so last October. But for some reason the Public Health Service has not yet taken the same step that the American Red Cross has taken, namely, when I wrote the letter, the Public Health Service took the position that a person who was an intravenous drug user, that group contributing 17 percent of AIDS cases, could not donate blood. I think the category used was: cannot donate.

The group that contributes 73 percent of the AIDS cases, that is, as of last August, male homosexuals, were in the should not donate category. And that is still the case today.

It is a little puzzling to me that the group that contributes 73 percent of the AIDS cases, male homosexuals, are in the should not donate category, meaning that they can donate but they should not, whereas the group that contributes 17 percent of the AIDS cases, intravenous drug users, is in the cannot donate category.

Now, would you please explain to me why the Public Health Service is reluctant to take the same step that the American Red Cross has taken to protect the integrity of the blood supply of the country?

Mr. KELSO. Mr. Dannemeyer, that sounds like a question that should be addressed to the Food and Drug Administration, and I really couldn't comment on it. But we can get back to you with some kind of response.

Mr. DANNEMEYER. I think the letter that I directed went to the Public Health Service, also the CDC. I don't think that the FDA has anything to do with that.

Mr. KELSO. Well, CDC, but it isn't under the purview of the Health Resources and Services Administration. I would be reluctant to comment on it. But we can get back to you with some kind of a response.

Mr. DANNEMEYER. Do any of the other witnesses choose to respond to that.

[No response.]

Mr. DANNEMEYER. I have a question for Mr. Smith. Is there any difficulty of patients establishing eligibility for Medicaid, given the fact that there is in some cases a relatively short time that elapses between the diagnosis of a case of AIDS and the death of the patient?

Mr. ELMER SMITH. Mr. Dannemeyer, I have not heard of any such instances. To qualify for Medicaid you have to meet the CDC definition of AIDS. And there are procedures available in the Social Security Administration district offices, for example, that you can get presumptive eligibility for the Supplemental Security Income Program, which in most States confers automatic eligibility for Medicaid as well. This is an expedited process where, within a relatively short period of time, people can qualify.

Mr. DANNEMEYER. Is there anything under existing law that would prevent or preclude a State or an agency within a State of applying for a waiver in order to implement health care delivery and management alternatives for AIDS patients?

Mr. ELMER SMITH. No. There are two forms of waivers, as I indicated earlier. There are so-called freedom of choice waivers, which allow case management techniques to be brought in and allow the persons under the waivers to be restricted to certain cost-effective and efficient providers. Second, the home and community-based service waivers focus on providing care in the community rather than in institutions.

Mr. DANNEMEYER. Have any applications for those kinds of waivers been received by your agency so far?

Mr. ELMER SMITH. Specifically directed at AIDS patients, we know of one State that is developing a waiver.

Mr. DANNEMEYER. Which one is that?

Mr. ELMER SMITH. That's the State of Colorado.

It's possible that some AIDS patients are being served under other waivers which are more broadly based than just AIDS patients. But we are not aware of any others that are specifically focused on AIDS patients per se.

Mr. DANNEMEYER. Has your agency received any applications for a waiver that have been turned down?

Mr. ELMER SMITH. For home and community-based service waivers that would focus on AIDS patients, no; no, sir.

Mr. DANNEMEYER. Thank you.

Thank you, Mr. Chairman.

Mr. WAXMAN. We obviously need much better information on the total cost of care to AIDS patients and on the cost and effectiveness of alternative forms of care that rely less on hospitalization. In HCFA's research and demonstration activities, you can test innovative approaches to the delivery of care to Medicaid and Medicare eligibles. What projects are you currently supporting with

regard to the AIDS population? What is the scope of these projects. And what do you hope to learn as a result of these efforts?

Mr. ELMER SMITH. Under the Research and Demonstration Program, Mr. Chairman, to the best of my knowledge we are not supporting any specific AIDS related projects per se. There are a lot of projects on alternative forms of care, a lot of projects on reimbursement rates, and so forth, but none specifically to my knowledge focused on provision of services to AIDS patients.

I do want to mention, however, the other two waivers, which are not research and demonstration waivers, but allow States to put together innovative packages for services to AIDS patients, the home and community-based service waivers, and the freedom of choice waivers.

Mr. WAXMAN. But as far as the agency and the Department of Health and Human Services that funds health services under Medicaid and Medicare, you are not funding any projects to look at alternative ways of delivery care; you are looking to see if the States are going to do it. And you have only had one State come in and ask for a specific waiver with respect to AIDS cases. Is that a correct statement?

Mr. ELMER SMITH. Thus far that's correct.

Mr. WAXMAN. Since AIDS is the Public Health Service's, the department's, and now the President's No. 1 public health problem, don't you think that it is at least worth HHS' while to gather data on this population, the costs involved and the public expenditures involved in the delivery of care?

Mr. ELMER SMITH. Yes, sir.

Mr. WAXMAN. And how do you think that ought to be done?

Mr. ELMER SMITH. We are trying to do it—I think you will find, as Dr. Altman said and those other people have said, you will find that, the data bases in the country are very fragmentary, very limited. We are all struggling to try to extract as much data as we can out of these limited data bases.

There are studies under——

Mr. WAXMAN. But you are not conducting some projects of your own to see what might work effectively as alternatives to what bills you're paying?

Mr. ELMER SMITH. We have the authority to do so in the two sets of waivers that I mentioned. Those are both left to the initiative of States to come in and make an application.

In addition, the CDC center and other parts of the Public Health Service are funding statistical research studies to try to get better information about costs and number of persons being served.

Mr. WAXMAN. I want to ask a question of Mr. Wren because I understand, Mr. Wren, you are the Medicaid waiver expert.

Mr. Smith has suggested in his testimony that AIDS patients might be part of a home and community waiver program. That program, as I understand it, is limited to people at risk of having to go into a nursing home or other long-term care institutions. Is that correct?

Mr. WREN. That is correct, yes.

Mr. WAXMAN. Do you have data on the number of AIDS patients in nursing homes?

Mr. WREN. No, we do not.

Mr. WAXMAN. As I understand it from States and AIDS groups, the number is very small. Most AIDS patients are in hospitals and, as you have heard, many may stay in these hospitals. Would HCFA approve a 2176 waiver for home and community based services that was designed for AIDS patients at risk of hospitalization?

Mr. WREN. If the requirements in the statute and the regulations were met, yes, we would certainly approve such a request.

Mr. WAXMAN. Well, the statute says as an alternative to nursing home, not hospitalization. Do you feel you have the power to give a waiver?

Mr. WREN. Under certain conditions, we have interpreted requests involving hospitalized individuals in such a fashion that such a request could be approved.

Mr. WAXMAN. You have had experience with this? You have granted a waiver in the past, along these lines?

Mr. WREN. Not with AIDS. We have not received a request for AIDS——

Mr. WAXMAN. No, no, as an alternative to hospitalization, you have granted a 2176 waiver?

Mr. WREN. Yes, Mr. Chairman.

Mr. WAXMAN. And where was that?

Mr. WREN. In a number of cases involving individuals, particularly children, who were respirator bound in hospitals, they would have been in a nursing home had such nursing home care been available.

Mr. WAXMAN. That would be the Katie Beckett type case?

Mr. WREN. That type of case, yes, sir.

Mr. WAXMAN. Would HCFA approve a 2176 waiver for services designed for AIDS and ARC, the AIDS related complex, patients at risk of long-term care? What criteria would the proposal have to meet? What services would be allowable under the waiver? And what cost criteria would apply?

Mr. WREN. Under the home and community based services waiver provision, Mr. Chairman, a number of statutory assurances must be met. These assurances are parroted pretty much in our regulations. With respect to services, there is an almost infinite array of services which could be provided, including hospice care, a number of in-home services, with the exception of room and board, which are specifically excluded under the statute.

Mr. WAXMAN. So, the services that you think would be allowable would include hospice care, community based home care——

Mr. WREN. We do not dictate to the States which services may be incorporated into an individual request. We leave that pretty much to the discretion of the State. But they must fall within the framework of the existing statute.

Mr. WAXMAN. I was going to ask you, have any States approached HCFA about using waivers to pay for alternate care for AIDS patients? Is it correct to say only——

Mr. WREN. I understand that one State is now formulating such a request. We have not yet received such a request.

Mr. WAXMAN. I see. And you haven't received one; therefore, you haven't acted on such a request yet?

Mr. WREN. We have not received one.

Mr. WAXMAN. Do you see any obstacles in the waiver program to using it for AIDS patients?

Mr. WREN. If the requirements of the statute and regulations are met, no, sir, I do not.

Mr. WAXMAN. The question is, will the terms of the statute and the regulations in any way prove to be an obstacle for granting a waiver for AIDS patients? Do you know? Do you have an estimate on that?

Mr. WREN. You used the term, "in any way," that could pose a problem, but if a request is within the framework of the law, no, sir, I do not see a problem.

Mr. WAXMAN. OK.

Dr. Altman recommended that we establish a home and community based waiver program specifically for AIDS patients. Do you see problems with this approach? How would you correct them, either one of you?

Mr. ELMER SMITH. Mr. Chairman, I would like to make one addition to Mr. Wren's remarks if I may. You have included ARC in your question. ARC per se is not a qualifying condition for Medicaid. So, persons with ARC, unless they have a combination of disabling conditions which would otherwise qualify them under the Social Security Administration definition, would not be covered.

To go to your second question that Dr. Altman raised, I think at this time I had not heard Dr. Altman's proposal earlier, but certainly speaking professionally and from my knowledge personally, my knowledge of the Medicaid Program, I don't believe that there is a need to establish another separate waiver program at this time. There is an enormous amount of flexibility under both freedom of choice and home and community based service waivers in terms of the services that can be provided, into the ways that they can be organized, into the authority to allow case management, and so forth.

I think that at this time I don't see any particular need for another diagnosis-based waiver per se.

Mr. WAXMAN. OK. Thank you very much.

Could you submit for the record model guidelines for the States applying for waivers?

Mr. ELMER SMITH. Yes. [See p. 79.]

Mr. WAXMAN. We are going to have additional questions we would like you to respond to for the record.

Mr. ELMER SMITH. Fine.

Mr. WAXMAN. That would be for all of the witnesses.

Mr. Nielson, do you have some questions of these witnesses?

Mr. NIELSON. I have been on an SEC hearing, so I apologize for arriving late.

We are having a cut in the AIDS funding this next year, primarily because of the imposition of Gramm-Rudman on March 1. To what extent will that impair your program, either Dr. Martin or Mr. Smith?

Mr. ELMER SMITH. Speaking for the Medicaid Program, Mr. Nielson, Gramm-Rudman does not apply to the Medicaid Program per se. So, that will not be a problem.

Mr. NIELSON. Dr. Martin or Mr. Kelso, either one.

Mr. KELSO. The $16 million for the AIDS demonstration project is up here for rescission; moreover 4.3 percent of the $16 million has been cut by Gramm-Rudman. But that would leave about $15.3 million, and I don't think the 4.3 percent cut would impair that program if Congress were to not go along with the rescission.

Mr. NIELSON. In your view, Mr. Kelso, are you giving sufficient emphasis to the AIDS problem, in other words, devoting a sufficient portion of your budget, enough serious emphasis to the program?

Mr. KELSO. I certainly think the Public Health Service is. Speaking for the Agency that I am responsible for, we view our role primarily as taking care of our beneficiaries and disseminating information on AIDS. I think we are fulfilling that.

Mr. NIELSON. Do you have any problems with the alternative care demonstration as proposed by the Appropriations Committee last year?

Mr. KELSO. Do you mean the $16 million demonstration project?

Mr. NIELSON. Yes. Do you have any problem with that?

Mr. KELSO. The reason that is up for rescission is that, quite frankly, we view the responsibility for care of AIDS patients as a State, local, private activity.

Mr. NIELSON. Do you plan to coordinate with the Robert Wood Johnson specialized program at all?

Mr. KELSO. Yes, sir, we certainly do.

Mr. NIELSON. How will that work?

Mr. KELSO. We have already met with them. We have formulated a draft joint agreement. If the $15.3 million becomes available, we would probably share grant applications and would be very sure that the Federal effort did not duplicate or take the place of anything that they are doing.

Mr. NIELSON. One question that is bothering me may not be your ball park, but let me try it anyway.

We hear many cases where the cost of an AIDS victim is many thousands of dollars, sometimes $20,000 and upward, up to $100,000. Often their Medicaid does not cover that. What would you recommend to solve this problem? Is there some kind of catastrophic type thing that could be added?

Mr. KELSO. If you're speaking of Medicare, I will ask Mr. Smith.

Mr. NIELSON. Yes. How do we solve that particular problem?

Mr. ELMER SMITH. That is a problem that I think the Robert Wood Johnson Foundation has the significant focus on, Mr. Nielson. And that is it is a problem which in the first instance is going to be solved at the local level through organizing a different pattern of services than are available in the highest cost places. I think that the high end of the spectrum on cost is usually considered to be New York City. This was related in large measure not only to the population being served but to the fact that they had a very heavy use of inpatient hospitalization.

The number of hospital days at one point in the past was 59 days, whereas in San Francisco it was around 12 days, and so forth.

Mr. NIELSON. Is there any evidence San Francisco is doing the job with cutting it by five that way? Is San Francisco neglecting some things New York is doing? Or is New York doing some things that San Francisco should be doing?

Mr. ELMER SMITH. There are two elements of difference between New York and San Francisco. One is that New York has a much higher proportion of IV drug users who have contracted AIDS. They are a difficult group to case manage and to handle. In San Francisco there is a much smaller proportion of those persons.

Other than that, I think that what we are seeing is that San Francisco has put together a very effective package of health services, social services, volunteer services in the community which has not been replicated to quite that degree in other parts of the country, although at this point in time we are aware that many cities and States are very interested in that pattern. Of course, that is specifically what the Robert Wood Johnson Foundation is trying to see replicated through its series of demonstration grants.

Mr. NIELSON. Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

You are all representing the administration in dealing with this AIDS care, delivery of care area. We talked about a rescission. The Reagan administration in the face of an epidemic is asking for a rescission of $41 million that already has been appropriated in a bill that was signed by the President. That $41 million was money that would go for research, epidemiology, testing, public education and information, as well as $15 million to look at demonstration projects for delivering alternative care.

Dr. Martin and Mr. Kelso, your statement is that the position of the Reagan administration is this is a problem that is primarily one at the local level, to look at alternative care systems to what we now are seeing in different parts of the country for AIDS patients.

If our Federal dollars are being used under Medicaid and rarely but sometimes under Medicare for AIDS patients, why isn't it the Federal Government's responsibility to try to figure out ways to deliver care in a more humane way and cost-effective way to use our dollars wisely and to perhaps save some of those dollars?

Dr. MARTIN. I think, first, it needs to be pointed out there is a substantial amount of money being expended which the administration did not propose for rescission, specifically directed at the high priorities of research and epidemiology.

The present administration position is that those lessons which in fact should and can be learned, we feel, are being carried out in the private sector at the State and local level. And from those lessons, without the expenditure of $16 million, we can learn the lessons that are necessary to apply to the broader reimbursement programs.

Mr. WAXMAN. We do have a financial interest in learning those lessons, how to use our money cost effectively, how to treat the patients more humanely, in a way that will be less expensive. Isn't that correct?

Dr. MARTIN. Yes, sir.

Mr. WAXMAN. And we are, therefore, hoping that the private sector and others may well do the job that will benefit the Federal taxpayers. Is that correct?

Dr. MARTIN. I think in any number of areas we are depending very heavily on the private sector to do exactly that.

Mr. WAXMAN. And if the private sector doesn't have the ability to follow the models and to learn alternative care, what should the Federal Government do?

Dr. MARTIN. Well, I——

Mr. WAXMAN. Accept the results and say: well, we'll have to continue to pay more money——

Dr. MARTIN. We have a great deal of——

Mr. WAXMAN [continuing]. Even though there might have been models of less costly care?

Dr. MARTIN. We have a great deal of confidence in the RWJ Foundation project and other activities. I think San Francisco itself proves the viability of those alternatives. I think if those efforts had failed, which most have not, we would probably reassess our position in a couple of years. We are very confident that they will succeed.

Mr. WAXMAN. It seems to me we have the ironic situation that you are saying as, an administration group of representatives, we expect the States and local governments to figure out how to take care of these patients in a less costly and more humane way. At the same time, you are also proposing that we put a ceiling on what the Federal Government will pay for the cost of care under Medicaid, which pays for maybe as many as 40 percent of the AIDS patients. So, we are telling the States: you do the job with less money, that will save the Federal Government more dollars, and be a humane way to approach these AIDS cases.

That seems to me a major contradiction and a guideline for a real failure to deal with an epidemic that is going to be resulting in the need for health care services for more and more patients, perhaps doubling the number of patients from year to year, if the present pattern persists.

I just say that not for your response but for the record. I view the totality of what you are saying to us as one that is completely inconsistent. We ought to be spending money on looking at alternative care. That is why Congress appropriated the $16 million. It is in our interest to do so, because alternatives will treat patients more humanely and use our dollars more effectively, and save dollars in fact. To cut back that $16 million, it seems to me, is not a very wise policy if we are trying to figure out how to deal with this epidemic in a rational way.

Mr. Dannemeyer or Mr. Nielson, any other comments before we move on to other witnesses?

Mr. DANNEMEYER. I have no further questions, Mr. Chairman.

Mr. WAXMAN. If not, we want to thank you very much for your testimony. We will look forward to additional answers for the record for questions we will have.

Our next panel will be Ms. Bevlyn Matthews from the Transamerica Occidental Insurance Co., and Mr. Mel Rosen from the New York State AIDS Institute, who will describe the State's new program for AIDS hospices.

Ms. Matthews will discuss Transamerica Occidental Insurance Co.'s policies for assisting policyholders with catastrophic illnesses and alternative care.

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We are pleased to have both of you with us today. Your prepared statements will be made part of the record in full. We would like to ask you to summarize in around 5 minutes.

Ms. Matthews.

STATEMENTS OF BEVLYN MATTHEWS, R.N., MANAGER OF PATIENT CARE SERVICES, TRANSAMERICA OCCIDENTAL LIFE INSURANCE CO.; AND MELVIN ROSEN, EXECUTIVE DIRECTOR, AIDS INSTITUTE, NEW YORK STATE DEPARTMENT OF HEALTH

Ms. MATTHEWS. Thank you, Mr. Chairman and members of the committee for this invitation to testify here today.

I am the manager of patient care services for Transamerica Occidental Life Insurance Co. of Los Angeles, CA. I am also a registered nurse.

I would like to give you a brief overview of how our patient care services program operates, specifically in the AIDS context, and then describe three recent AIDS case histories and how they were handled in a cost-effective and sensitive manner.

Transamerica Occidental is the ninth largest life insurer in the United States in terms of insurance in force. Gross revenues for group health insurance premiums and premium equivalents are over $1 billion annually. Transamerica Occidental does not market individual health insurance.

Our group contracts provide coverage for the reasonably necessary services and supplies specified in the contract for the diagnosis and care of an insured person's illness. Coverage is limited to the usual and customary charges within the given geographic area.

A claim for AIDS is handled the same as any other claim for illness. Charges and services are reviewed based on the current usual treatment for the condition, associated fees and processed in accordance with the specific policy provisions.

Because AIDS claims may involve long-term extensive care, the files are referred to the patient care services area, as are other catastrophic illnesses or injuries such as head trauma, spinal cord injury or stroke. The department assists insured people to better understand their group health insurance benefits and to seek cost effective medical treatment. Department personnel coordinate medical care on catastrophic claims, helping the insured person to make the most effective use of medical insurance dollars available.

Because of our work with these catastrophic illness and injuries, we can make sure that the individual is aware of all the available resources. Our work is also strictly confidential.

We have not set up special guidelines for AIDS in the claims processing area because we feel it is important to treat all insureds equally and provide benefits they are entitled to under the contract in a timely and accurate manner without regard to the specific illness.

However, Transamerica Occidental does provide registered nurse consultants and health insurance coordinators in our patient care services department to assist patients with early discharge from the hospital when prescribed by the attending physician. They will also coordinate the patient's prescribed alternative forms of medical treatment and rehabilitative services.

Our objective is to assist our insureds to receive quality health care without unnecessary expense. This often translates into helping a patient avoid exceeding policy dollars limits, after which he or she may lose coverage completely. Our registered nurse consultants and health insurance coordinators recognize that each individual is unique, and health care is tailored to meet their particular individual needs.

When a case is first referred to patient care services, a registered nurse consultant conducts an initial evaluation to determine the patient's medical need. Depending on the patient's particular situation, the consultant then works with the attending physician, the patient, and the family to develop an alternative treatment program. The consultant will then help identify alternatives to hospitalization and eliminate any unnecessary expenses.

The attending physician will prescribe the necessary treatment for an illness or injury, but many times this treatment can be provided in many different ways. Home health care and hospice care are two examples of alternate methods of delivering prescribed care, often at a much lower cost than hospitalization.

In essence, the consultant and coordinator serve as advocates and trouble shooters for the patient. Because they are personally involved from the outset, they become information resources for the patient and family as well as for doctors and other health care professionals. They help meet the medical, psychosocial and financial needs of the patient and the family.

Transamerica Occidental is a leader in developing and providing patient care services to its insureds. We have offered catastrophic care and rehabilitation services since 1978 and now we offer these services to insureds diagnosed as having the disease AIDS.

As of December 1985, we had a total of 14 AIDS cases referred to patient care services. The insured medical bills for these 14 patients total $768,000, or an average cost of $55,000 per case.

Mr. WAXMAN. Ms. Matthews, I notice you are reading the statement. It is a lengthy one. But we do have the full statement for the record. If you want to give a summarizing statement, we would like to go on to Mr. Rosen so we will have time to ask you questions and get answers for the record.

Ms. MATTHEWS. Should I go over, Mr. Chairman, the three patients that we have reviewed? It does involve a lot of the cost.

Mr. WAXMAN. Why don't you give one of the examples? We will have the others in the record to read, and, of course, some of us have had a chance to read through this as you have been talking, and before the hearing.

Ms. MATTHEWS. Could I suggest, due to the vast differences, that I use maybe the last two? They really are quite different.

OK?

Mr. WAXMAN. Surely.

Ms. MATTHEWS. Thank you.

This man was aged 65. He began showing symptoms in March 1984. There was no definitive diagnosis until he was diagnosed in September 1985. He entered the hospital with a diagnosis of pneumonia. He stayed in the hospital for 39 days at a cost of $32,764.

At that point we assisted him in transition to home through a Home Hospice Program. When he first went home, this man's con-

dition only required the services of a skilled registered nurse for approximately 2 hours a day. His condition regressed, and he needed nursing attendant services 24 hours a day in order to remain at home.

His group health policy did not provide for this service. So, with his permission we went to the policyholder, his employer, to explain his special circumstances and needs. We asked for a special agreement separate from his group health insurance. This agreement would allow him to be treated at home. The policyholder agreed to pay for these expenses for their employee and also that this agreement would be extended to other employees under similar circumstances.

The individual spent a total of 47 days in the Home Hospice Program before he died at home. The total costs were $3,945. This same treatment in the hospital would have cost an estimated $39,950. There was a saving of $36,005 by providing home hospice care.

The other example——

Mr. WAXMAN. That $36,000 was for one patient alone?

Ms. MATTHEWS. Yes, the saving on one patient. It was anticipated that his hospital costs would be almost $40,000 for the 47 days that he spent in the Home Hospice Program, had he not been in that program.

The other example that I will give is a child who was born in 1982 who was injured in an auto accident at the age of 9 months. He contracted AIDS as a result of a blood transfusion he received after the accident.

We assumed claims liability for this child in 1984 after his coverage was transferred to us from an HMO during an open enrollment period. By the age of 3, it was apparent that this little boy who lives with his mother did not have normal growth, and development was delayed. He could not sit up alone. He could not speak and was being fed through a tube in his stomach.

He was treated with intravenous immunoglobin in an attempt to build up his immune system. Every 3 to 6 weeks he receives this treatment. He has unfortunately been plagued with respiratory infections and fevers. So, extreme care must be taken to prevent this child from contracting any of the normal childhood diseases, which would no doubt be fatal due to his already compromised immune system.

He even has to be protected from his own bodily excrement, which is a source of infection. He is constantly kept clean and monitored. A constant watch must be made to see that his lungs remain clear and that he doesn't get infections via the tube into his stomach.

It really is not exaggerating to say that a diaper rash could kill this child.

I am happy, though, to say that he is still alive. He has reached his fourth birthday and is being treated at home. His mother is now working. This is the result of a difficult search that we conducted to find a nursing agency that will provide 24-hour in-home care for this child with AIDS. This agency still has difficulty in getting employees who will work with AIDS patients, but the child is getting the care he needs.

He also receives physical therapy at home to keep his little muscles aligned so that, if he does grow up, he will not be severely disabled.

Registered nurses provide the extensive high tech nursing services required to provide for this patient. They also provide psychological support to the family.

Even with a 24-hour skilled pediatric care, the child must go to the hospital periodically for active treatment. He has also been admitted for several infections. As of December 1985, he had incurred $332,300 in claims expense. This figure does not include the 2 years that he was enrolled under the HMO program.

Mr. WAXMAN. Thank you very much, Ms. Matthews. We have the rest of the statement. It will be part of the record. I appreciate your presentation to us.

[Testimony resumes on p. 141.]

[The prepared statement of Bevlyn Matthews follows:]

BEVLYN MATTHEWS, R.N.
MANAGER OF PATIENT CARE SERVICES
TRANSAMERICA OCCIDENTAL LIFE INSURANCE COMPANY

I'M BEVLYN MATTHEWS. I'M THE MANAGER OF PATIENT CARE SERVICES FOR TRANSAMERICA OCCIDENTAL LIFE INSURANCE COMPANY OF LOS ANGELES, CALIFORNIA. I AM ALSO A REGISTERED NURSE.

I WOULD LIKE TO GIVE YOU A BRIEF OVERVIEW OF HOW OUR PATIENT CARE SERVICE PROGRAM OPERATES — SPECIFICALLY IN THE AIDS CONTEXT — AND THEN DESCRIBE THREE RECENT AIDS CASE HISTORIES AND HOW THEY WERE HANDLED IN A COST-EFFECTIVE AND SENSITIVE MANNER.

TRANSAMERICA OCCIDENTAL IS THE NINTH LARGEST LIFE INSURER IN THE UNITED STATES IN TERMS OF INSURANCE IN FORCE. GROSS REVENUES FOR GROUP HEALTH INSURANCE PREMIUM AND PREMIUM EQUIVALENT ARE OVER $1 BILLION ANNUALLY. TRANSAMERICA OCCIDENTAL DOES NOT MARKET INDIVIDUAL HEALTH INSURANCE.

OUR GROUP CONTRACTS PROVIDE COVERAGE FOR THE REASONABLY NECESSARY SERVICES AND SUPPLIES SPECIFIED IN THE CONTRACT FOR THE DIAGNOSIS AND CARE OF AN INSURED PERSON'S ILLNESS. COVERAGE IS LIMITED TO THE USUAL AND CUSTOMARY CHARGES WITHIN THE GEOGRAPHICAL AREA.

A CLAIM FOR TREATMENT OF AIDS IS HANDLED THE SAME AS ANY OTHER

ILLNESS. CHARGES AND SERVICES ARE REVIEWED BASED ON THE CURRENT USUAL TREATMENT FOR THE CONDITION, ASSOCIATED FEES AND PROCESSED IN ACCORDANCE WITH THE SPECIFIC POLICY PROVISIONS.

BECAUSE AIDS CLAIMS MAY INVOLVE LONG TERM EXTENSIVE CARE, THE FILES ARE REFERRED TO THE PATIENT CARE SERVICES AREA AS ARE OTHER CATASTROPHIC ILLNESSES OR INJURIES SUCH AS HEAD TRAUMA, SPINAL CORD INJURY OR STROKE. THE DEPARTMENT ASSISTS INSURED PEOPLE TO BETTER UNDERSTAND THEIR GROUP HEALTH INSURANCE BENEFITS AND TO SEEK COST EFFECTIVE MEDICAL TREATMENT. DEPARTMENT PERSONNEL COORDINATE MEDICAL CARE ON CATASTROPHIC CLAIMS, HELPING THE INSURED PERSON TO MAKE THE MOST EFFICIENT USE OF THE MEDICAL INSURANCE DOLLARS AVAILABLE. BECAUSE OF OUR WORK WITH CATASTROPHIC INJURIES AND ILLNESSES, WE CAN MAKE SURE THE INDIVIDUAL IS AWARE OF ALL THE AVAILABLE RESOURCES. OUR WORK IS ALSO STRICTLY CONFIDENTIAL.

WE HAVE NOT SET UP SPECIAL GUIDELINES FOR AIDS IN THE CLAIMS PROCESSING AREA BECAUSE WE FEEL IT IS IMPORTANT TO TREAT ALL INSUREDS EQUALLY AND PROVIDE THE BENEFITS THEY ARE ENTITLED TO UNDER OUR

CONTRACTS IN A TIMELY AND ACCURATE MANNER WITHOUT REGARD TO THE SPECIFIC ILLNESS.

HOWEVER, TRANSAMERICA OCCIDENTAL DOES PROVIDE REGISTERED NURSE CONSULTANTS AND HEALTH INSURANCE COORDINATORS IN OUR PATIENT CARE SERVICES DEPARTMENT TO ASSIST PATIENTS WITH EARLY DISCHARGE FROM THE HOSPITAL WHEN PRESCRIBED BY THE ATTENDING PHYSICIAN. THEY WILL ALSO COORDINATE THE PATIENT'S PRESCRIBED ALTERNATE FORMS OF MEDICAL TREATMENT AND REHABILITATIVE SERVICES. OUR OBJECTIVE IS TO ASSIST OUR INSUREDS TO RECEIVE QUALITY HEALTH CARE WITHOUT UNNECESSARY EXPENSE. THIS OFTEN TRANSLATES INTO HELPING A PATIENT AVOID EXCEEDING THE POLICY DOLLARS LIMITS, AFTER WHICH HE OR SHE MAY LOSE COVERAGE COMPLETELY. OUR REGISTERED NURSE CONSULTANTS AND HEALTH INSURANCE COORDINATORS RECOGNIZE THAT EACH INDIVIDUAL IS UNIQUE, AND HEALTH CARE IS TAILORED TO MEET THEIR PARTICULAR INDIVIDUAL NEEDS.

WHEN A CASE IS FIRST REFERRED TO PATIENT CARE SERVICES A REGISTERED NURSE CONSULTANT CONDUCTS AN INITIAL EVALUATION TO DETERMINE THE PATIENTS MEDICAL NEEDS.

DEPENDING ON THE PATIENT'S PARTICULAR SITUATION THE CONSULTANT THEN WORKS WITH THE ATTENDING PHYSICIAN, THE PATIENT AND THE FAMILY TO DEVELOP AN ALTERNATE TREATMENT PROGRAM.

THE CONSULTANT WILL THEN HELP IDENTIFY ALTERNATIVES TO HOSPITILIZATION AND ELIMINATE ANY UNNECESSARY EXPENSES.

THE ATTENDING PHYSICIAN WILL PRESCRIBE THE NECESSARY TREATMENT FOR ILLNESS, BUT MANY TIMES THIS TREATMENT CAN BE PROVIDED IN MANY DIFFERENT WAYS. HOME HEALTH CARE AND HOSPICE CARE ARE TWO EXAMPLES OF ALTERNATE METHODS OF DELIVERING PRESCRIBED CARE, OFTEN AT MUCH LOWER COSTS THAN FOR HOSPITILIZATION.

IN ESSENCE, THE CONSULTANT AND COORDINATOR SERVE AS ADVOCATES AND TROUBLE SHOOTERS FOR THE PATIENT. BECAUSE THEY ARE PERSONALLY INVOLVED FROM THE OUTSET, THEY BECOME INFORMATION RESOURCES FOR THE PATIENT AND FAMILY AS WELL AS FOR DOCTORS AND OTHER HEALTH CARE PROFESSIONALS. THEY HELP MEET THE MEDICAL, PSYCHOSOCIAL AND FINANCIAL NEEDS OF THE PATIENT AND FAMILY.

TRANSAMERICA OCCIDENTAL IS A LEADER IN DEVELOPING AND PROVIDING

PATIENT CARE SERVICES TO ITS INSUREDS. WE HAVE OFFERED CATASTROPHIC CARE AND REHABILITATION SERVICES SINCE 1978 AND NOW WE OFFER THESE SERVICES TO INSUREDS DIAGNOSED AS HAVING THE DISEASE AIDS.

AS OF DECEMBER 1985, WE HAVE HAD A TOTAL OF 14 AIDS CASES REFERRED TO PATIENT CARE SERVICES. THE INSURED MEDICAL BILLS FOR THESE 14 PATIENTS TOTAL $768,000, OR AN AVERAGE OF $55,000 PER CASE. HOWEVER, MOST OF THESE CASES ARE ONGOING.

I WOULD LIKE TO REVIEW FOR YOU THREE OF OUR CASES, SO YOU MAY HAVE A CLEARER PICTURE OF OUR WORK IN PATIENT CARE SERVICES.

THE FIRST PATIENT WAS A MAN WHO WAS 58 YEARS OLD WHEN HE WAS REFERRED TO US. MEDICAL BILLS STARTED COMING IN TO THE COMPANY IN SEPTEMBER OF 1984. THE ORIGINAL DIAGNOSIS WAS FATIGUE AND FEVER OF UNKNOWN ORIGIN. BY NOVEMBER OF 1984 HE WAS NO LONGER WELL ENOUGH TO CONTINUE WORKING.

IN MAY OF 1985, THIS MAN WAS HOSPITALIZED AND DIAGNOSED AS HAVING AIDS. FOR 27 DAYS OF HOSPITALIZATION, WE PAID $21,538 IN HOSPITAL COSTS. HE KNEW THAT HE WAS VERY ILL, AND HE WANTED TO GO HOME. HE

WAS PARALYZED IN BOTH LEGS. HE HAD DIFFICULTY BREATHING, SOME SLURRING OF SPEECH AND HE HAD LOST CONTROL OF HIS BOWEL AND BLADDER. HIS PHYSICIANS AGREED THAT IT WOULD BE SAFE FOR HIM TO BE CARED FOR AT HOME. DURING THIS TIME, HE HAD A NURSING ATTENDANT 24 HOURS A DAY, AND WAS PROVIDED WITH THE NECESSARY MEDICAL EQUIPMENT AND SUPPLIES. THIS INCLUDED A HOSPITAL BED, A SPECIAL LIFT SINCE HE WAS TOO WEAK TO GET OUT OF BED, AND A COMMODE CHAIR. HE ALSO RECEIVED SUPERVISORY VISITS ONCE A WEEK FROM A HOME HEALTH AGENCY REGISTERED NURSE.

THE TREATMENT WAS SAFE, AND IT GAVE HIM WHAT HE DESIRED, WHICH WAS TO DIE AT HOME AND NOT IN THE HOSPITAL. HE DIED 13 DAYS AFTER GOING HOME. THE COST OF HIS HEALTH CARE FOR THOSE DAYS WAS A TOTAL OF $4,602. HIS TOTAL MEDICAL BILL, INCLUDING DOCTORS, HOME HEALTH CARE AND HOSPITAL COSTS WAS $28,140. HIS AVERAGE HOSPITAL COST PER DAY WAS $850. HAD HE REMAINED IN THE HOSPITAL FOR HIS LAST THIRTEEN DAYS, THE ESTIMATED COST WOULD HAVE BEEN $11,000. BEING TREATED AT HOME SAVED $6,402 AND MET THE PATIENT'S WISHES.

THE SECOND CASE WAS A MAN, AGE 56, WHO BEGAN SHOWING SYMPTOMS IN

MARCH OF 1984. THERE WAS NO DEFINITIVE DIAGNOSIS UNTIL HE WAS HOSPITALIZED IN SEPTEMBER, 1985. HE ENTERED THE HOSPITAL WITH A DIAGNOSIS OF PNEUMONIA. HE STAYED IN HOSPITAL FOR 39 DAYS, AT A COST OF $32,764. AT THAT POINT, WE ASSISTED HIM IN THE TRANSITION TO HOME THROUGH A HOME HOSPICE PROGRAM. WHEN HE FIRST WENT HOME, THIS MAN'S CONDITION ONLY REQUIRED A SKILLED REGISTERED NURSE TO VISIT FOR APPROXIMATELY 2 HOURS A DAY TO MONITOR HIS CONDITION, EVALUATE THE PAIN LEVEL AND ASSIST WITH PERSONAL HYGIENE.

HOWEVER, HIS CONDITION REGRESSED VERY RAPIDLY, AND HE NEEDED NURSING ATTENDANT SERVICES 24 HOURS A DAY IN ORDER TO REMAIN AT HOME. HIS GROUP HEALTH INSURANCE POLICY DID NOT PROVIDE FOR THIS SERVICE, SO WITH HIS PERMISSION WE WENT TO THE POLICYHOLDER, HIS EMPLOYER, TO EXPLAIN HIS SPECIAL CIRCUMSTANCES AND NEEDS. WE ASKED FOR A SPECIAL AGREEMENT, SEPARATE FROM HIS GROUP HEALTH INSURANCE. THIS AGREEMENT WOULD ALLOW HIM TO BE TREATED AT HOME. THE POLICYHOLDER AGREED TO PAY THE EXPENSES FOR THEIR EMPLOYEE. THIS AGREEMENT WOULD ALSO BE EXTENDED TO ANY OTHER EMPLOYEE UNDER SIMILAR CIRCUMSTANCES. WE

CONVINCED THEM THAT HOME CARE FOR THIS MAN CASE WAS A VIABLE, SAFE, AND COST-EFFECTIVE ALTERNATIVE TO HOSPITALIZATION. I'D LIKE TO STRESS THAT ALL DECISIONS WERE MADE WITH THE APPROVAL OF THE PATIENT AND THE ATTENDING PHYSICIAN. OUR PRIMARY CONCERN IS ALWAYS FOR THE SAFE AND EFFECTIVE CARE OF THE PATIENT.

THIS INDIVIDUAL SPENT A TOTAL OF 47 DAYS IN THE HOME HOSPICE PROGRAM, BEFORE HE DIED, AT HOME. THE TOTAL COSTS WERE $3,945. THIS SAME TREATMENT IN A HOSPITAL WOULD HAVE COST AN ESTIMATED $39,950. THERE WAS A SAVING OF $36,005 BY PROVIDING HOME HOSPICE CARE. AGAIN, WE WERE ABLE TO ENSURE THAT THE PATIENT WAS PROPERLY CARED FOR.

THE FINAL EXAMPLE INVOLVES A CHILD BORN IN 1982 WHO WAS INJURED IN AN AUTO ACCIDENT AT THE AGE OF 9 MONTHS. HE CONTRACTED AIDS AS A RESULT OF THE BLOOD TRANSFUSION HE RECEIVED AFTER THE ACCIDENT. WE ASSUMED CLAIMS LIABILITY FOR THE CHILD IN AUGUST, 1984, AFTER HIS COVERAGE WAS TRANSFERRED TO US, FROM AN HMO, DURING AN OPEN ENROLLMENT PERIOD.

BY THE AGE OF THREE, IT WAS APPARENT THAT THIS LITTLE BOY, WHO

LIVES WITH HIS MOTHER, DID NOT HAVE NORMAL GROWTH, AND DEVELOPMENT WAS DELAYED. HE COULD NOT SIT UP ALONE, AND HE COULD NOT SPEAK. HE WAS BEING FED THROUGH A TUBE INTO HIS STOMACH.

TODAY HE IS TREATED WITH INTRAVENOUS IMMUNOGLOBULIN IN AN ATTEMPT TO BUILD UP HIS IMMUNE SYSTEM. EVERY THREE TO SIX WEEKS HE RECEIVES THIS TREATMENT. BUT UNFORTUNATELY HE HAS BEEN PLAGUED WITH RESPIRATORY INFECTIONS AND FEVERS. EXTREME CARE HAS MUST BE TAKEN TO PREVENT THIS CHILD FROM CONTRACTING ANY OF THE NORMAL CHILDHOOD DISEASES WHICH WOULD NO DOUBT BE FATAL DUE TO HIS ALREADY COMPROMISED IMMUNE SYSTEM. HE MUST BE PROTECTED FROM ALL SOURCES OF INFECTION INCLUDING CONTACT WITH HIS OWN BODILY EXCREMENT.

HE IS CONSTANTLY MONITORED AND KEPT CLEAN. CONSTANT WATCH MUST BE MADE TO SEE THAT HIS LUNGS REMAIN CLEAR AND THAT HE DOESN'T GET AN INFECTION FROM THE FEEDING TUBE INTO HIS STOMACH. IT IS NOT EXAGGERATING TO SAY THAT A DIAPER RASH COULD KILL THIS CHILD.

I AM HAPPY TO SAY HE IS STILL ALIVE. HE HAS REACHED HIS FOURTH BIRTHDAY AND IS BEING TREATED AT HOME, AND HIS MOTHER IS NOW WORKING.

THIS IS THE RESULT OF A DIFFICULT SEARCH TO FIND A NURSING AGENCY THAT WOULD PROVIDE 24 HOUR IN-HOME CARE FOR A CHILD WITH AIDS. THIS AGENCY STILL HAS DIFFICULTY GETTING EMPLOYEES WHO WILL WORK WITH AIDS PATIENTS, BUT THIS CHILD IS GETTING THE CARE HE NEEDS. HE ALSO RECEIVES PHYSICAL THERAPY AT HOME TO KEEP HIS LITTLE MUSCLES IN ALIGNMENT, SO THAT IF HE DOES GROW UP, HE WON'T BE SEVERELY DISABLED. REGISTERED NURSES PROVIDE THE EXTENSIVE HI-TECHNOLOGY NURSING SERVICES REQUIRED AS WELL AS PROVIDE PSYCHOLOGICAL SUPPORT TO THE FAMILY. AND HIS MOTHER IS ABLE TO REMAIN EMPLOYED, WHICH IS EMOTIONALLY AS WELL AS FINANCIALLY VALUABLE TO HER AND THIS FAMILY.

EVEN WITH 24-HOUR SKILLED PEDIATRIC CARE, THE CHILD MUST GO TO THE HOSPITAL PERIODICALLY FOR ACTIVE TREATMENT. HE HAS ALSO BEEN ADMITTED FOR TREATMENT OF VARIOUS INFECTIONS. AS OF DECEMBER OF 1985, HE HAD INCURRED $332,300 IN CLAIMS EXPENSES. BUT IF HE WERE TO BE IN A HOSPITAL, HE WOULD REQUIRE A PRIVATE ROOM TO PROTECT HIM FROM INFECTIONS AND SPECIAL PEDIATRIC PRIVATE DUTY NURSES, AT A COST OF BETWEEN $1,200 AND $1,500 A DAY. BY PROVIDING FOR HIM AT HOME, HIS

TREATMENT COSTS ARE APPROXIMATELY 1/2 TO 2/3 OF WHAT THEY WOULD BE IN HOSPITAL. AND THE CHILD IS AT HOME, WITH HIS MOTHER.

THESE THREE EXAMPLES GIVE A PICTURE OF WHAT WE CAN ACHIEVE IN PATIENT CARE SERVICES AT TRANSAMERICA OCCIDENTAL INSURANCE COMPANY. WE GIVE AIDS PATIENTS THE SAME ATTENTION WE GIVE TO BURN VICTIMS, HEART ATTACK VICTIMS, PNEUMONIA VICTIMS AND OTHERS WHO HAVE SUFFERED CATASTROPHIC ILLNESSES OR INJURIES. WE HELP FIND COST SAVINGS THAT CAN ALLOW A PATIENT TO MAKE BEST USE OF THE BENEFIT DOLLARS UNDER HIS OR HER POLICY, WHILE INSURING THE BEST POSSIBLE CARE UNDER THE BEST POSSIBLE CONDITIONS. THIS IS A COMMITMENT MY COMPANY HAS MADE WHICH ENTAILS WORKING DIRECTLY WITH THE INSUREDS THEMSELVES. THIS IS NOT NECESSARILY THE EASIEST COURSE TO FOLLOW, BUT I THINK IT'S THE BEST COURSE, BOTH IN TERMS OF

COST EFFECTIVENESS AND TREATING INDIVIDUALS WITH THE DIGNITY THEY DESERVE WHEN THEY NEED IT MOST.

THANK YOU.

Mr. WAXMAN. Mr. Rosen, if you would summarize your statement in around 5 minutes, we would appreciate it.

STATEMENT OF MELVIN ROSEN

Mr. ROSEN. Mr. Chairman, Commissioner Axelrod asked me to convey to you the thanks of Governor Cuomo for all the work that you have done for people with AIDS and with issues around this epidemic since the very beginning, and I would also like to thank you.

What I have here—and I won't read the whole thing—is really a summary. I have the flu today, I'm sorry. It's a summary. So, I will try to go over all this.

New York State is about to embark on a brand-new program, and no State will have the comprehensive type of program that we will have. Basically, the problem has been that hospital and community services have not been coordinated in a comprehensive manner. The average length of stays and frequency of hospitalizations have been increased for patients who could better be served at home, as we have been talking about today.

It is estimated that the average cost of an AIDS patient's hospitalization exceeds $100,000 over several hospitalizations, with 21 days being the average length of stay in New York for each hospitalization. There is a severe lack of adequate data on AIDS patients in terms of hospitalization, utilization of outpatient services, and unnecessary hospitalization due to discharge planning problems.

The New York State Department of Health AIDS Institute is developing a program which will address the above problems on three levels: one, in-hospital care; two, outpatient referrals; and, three, data collection. Through the use of its regulatory powers, New York State is moving to establish a number of comprehensive AIDS care centers in New York City and upstate. These designated care centers will provide and or arrange for all levels of care and services required by the AIDS patient both in and out of the hospital including ambulatory and inpatient services, home health care and personal care services, psychosocial and psychiatric services, arrangements for needed housing, legal and financial assistance, and appropriate hospice and residential health care services.

Each patient in a designated care center will be provided with an in- and out-patient management plan and case manager who will identify the full range of services needed and how they will be provided.

The comprehensive care center case manager will be responsible for followup of service referrals and ongoing monitoring of the implementation of the patient management plan, both in and out of the hospital.

The AIDS intervention management system, AIMS, will be implemented to oversee the effectiveness and monitor the development of the designated care centers. The AIMS system will have four components: utilization review, to systematically monitor resource use; quality assurance, to determine the appropriate use of ancillary services and their responsiveness to the needs of the individual patient; case management review, to reflect a patient advocacy role where continuity of care, patient plan management, and

periodic monitoring and counseling are to be provided by the designated care center or its referral agency; and systems performance, to provide data related to length of stay, level of care, level of patient satisfaction, and cost information by patient category.

The AIMS program will provide a computerized information feedback loop providing the department of health and institutions within our system with up-to-date information on costs, patient characteristics, services provided, patient satisfaction and case management model comparisons.

Over the past 2½ years, New York State has spent $13 million, most of it on the development of a statewide AIDS community service system. Next year New York State will spend almost $10 million, much of that to expand the system. Other community care providers will be identified and provided with technical and financial support to develop as providers for nonhospital outpatient services. The community care network would be greatly enhanced by receipt of New York State's share of $16 million, appropriated by Congress this year for community based demonstration projects.

This would ensure provision and adequate reimbursement for nontraditional services that are part of the full continuum of services that must be provided if this system is to both increase patient satisfaction while reducing costs.

It is anticipated that the implementation of the above system will result in improved care for persons with AIDS. This will be true in a hospital where the care of the patient will be more closely coordinated. In addition, patients will be spending less time in the hospital, since the system encourages outpatient or ambulatory and enhanced community based services. Thus, patient satisfaction and quality of life would be enhanced.

The State expects to slow the rate at which AIDS related hospital costs are increasing by reducing the average length of stay by about one-half and the frequency of hospitalization through the coordination of hospital and community based systems.

Recommendations: In the area of nonhospital care settings a critical problem is the general lack of hospice level facilities. We recommend that Medicaid coverage be made available for hospice level care. And we have submitted a State plan amendment to HCFA for this, sir.

Medicare places a heavy emphasis in its reimbursement policies on direct medical care rather than supportive nursing care or other psychosocial services. We recommend that the Medicare Program provide coverage for a wider range of community based services so as to facilitate discharge from the hospital. Related to this problem is the need to ensure that eligibility waiting periods are waived so that patients don't die before Medicare coverage begins.

We strongly oppose the administration's proposal to cap Federal Medicaid payments which, combined with the increasing costs of services to AIDS patients, will result in an intolerable burden on the State. The State currently estimates a $400 million Medicaid shortfall between projected costs and the proposed cap. This shortfall will exacerbate the problem of providing adequate services to people with AIDS.

As we move toward Medicare DRG based rates, it is critical that adequate reimbursement be provided to reflect the level and intensity of services required by AIDS patients.

In summary, the State recommends that Medicaid, Medicare, and SSI coverage be modified to support a wider range of medical and related services. If we want to prevent the unnecessary hospitalization of AIDS patients, Federal support for various levels of care such as hospice, home health and other nontraditional services must be provided.

Thank you, sir.

[The prepared statement of Melvin Rosen follows:]

Statement of Melvin Rosen
Executive Director
AIDS Institute
Office of Public Health
Department of Health
State of New York

Testimony presented to the
Committee on Energy and Commerce
Subcommittee on Health and the Environment
United States House of Representatives

On A Comprehensive Care Program for AIDS Patients

March 5, 1986

DESCRIPTION OF THE PROBLEM

o It is estimated that there were 5,811 known persons with AIDS in New York State as of January 1986. The number of diagnosed AIDS patients is projected to double within 24 months, and continue to grow at that rate through the rest of the decade.

o The number of average monthly hospital AIDS admissions was 473 in 1985 with an average monthly increase in admissions of 3.5 percent.

o Persons with AIDS fall into several major risk groups which are characterized by differences in health, social and support requirements:

- Gay and bisexual men 63%
- IV drug users and their sex partners 35%
- Offspring of at-risk individuals 2%

o Hospital and community services are not coordinated in a comprehensive manner, thus the average length of stays and frequency of hospitalization may be increased for patients who could be better served at home on an outpatient basis.

o It is estimated that the average cost of an AIDS patient's hospitalization exceeds $100,000 over several hospitalizations with 21 days being the average length of stay for each hospitalization.

o There is a severe lack of adequate data on AIDS patients in terms of hospitalization, utilization of outpatient services and unnecessary hospitalization due to discharge planning problems.

THE PROPOSED SOLUTION IN NEW YORK STATE

o The New York State Department of Health's AIDS Institute is developing a program which will address the above problems on three levels: in-hospital care, outpatient referrals, and data collection.

o Through the use of its regulatory powers, New York State is moving to establish a number of comprehensive AIDS care centers in New York City and upstate. These designated care centers will provide or arrange for all levels of care and services required by the AIDS patient, including ambulatory and inpatient services, home health care and personal care services, psychosocial and psychiatric services, arrangements for needed housing, legal and financial assistance and appropriate hospice and residential health care services.

o Each patient in a designated care center will be provided with a patient management plan which will identify the full range of services needed and how they will be provided.

o The comprehensive care center (case managem-) will be responsible for follow-up of service referrals and on-going monitoring of the implementation of the patient management plan. (both in- and outpatient)

o The AIDS Intervention Management System (AIMS) will be implemented to oversee the effectiveness and monitor the development of the designated care centers. The AIMS systems will have four components.

o Utilization Review - to systematically monitor resource use;

o Quality Assurance - to determine the appropriate use of ancilliary services and their responsiveness to the needs of the individual patient;

o Case Management (revised) - to reflect a patient advocacy role where continuity of care, patient plan management and periodic monitoring and counseling are to be provided by the designated care center or its referral agency; and,

o Systems Performance - to provide data related to length of stay, level of care, level of patient satisfaction and cost information by patient category.

The AIMS program will provide a computerized information feedback loop ~~reporting~~ providing the Department of Health and institutions within our system with up-to-date information on costs, patient characteristics, services provided and rating patient satisfaction and Case Management model comparisons.

a ~~comprehensive community based system~~ ... amount of that to expand that system.

o Other Community Care Providers ~~are being~~ will be identified and provided with technical and financial support to develop them as providers for non-hospital ~~based~~ outpatient services. ~~For the most part these agencies reflect the model of the Gay Men's Health Crisis, Inc. which is based upon a volunteer base to provide a wide range of services.~~ The community care network would be greatly enhanced by receipt of New York State's share of the $16 million appropriated by Congress this year for community based demonstration projects. This would insure provision and adequate reimbursement for non traditional services that are part of the full continuum of services that must be provided if this system is to both increase patient satisfaction while reducing costs.

PROGRAMMATIC GOALS AND EXPECTATIONS

o It is anticipated that the implementation of the above system will result in improved care for persons with AIDS. This would be true in the hospital where the care of the patients will be more closely coordinated. In addition, patients will be spending less time in the hospital since the system encourages outpatient or ambulatory care and enhanced community based services. Thus, patient satisfaction and quality of life would be enhanced.

o The State expects to slow the rate at which AIDS related IV drug hospital costs are increasing by reducing the average length of stays and the frequency of hospitalization through the coordination of hospital and community based care.

RECOMMENDATIONS

o In the area of non-hospital care settings a critical problem is the general lack of hospice level facilities. We recommend that Medicaid coverage be made available for hospice level care.

o Medicare places a heavy emphasis in its reimbursement policies on direct medical care rather than supportive nursing care or other psychosocial services. We recommend that the Medicare program provide coverage for a wider range of community based services so as to facilitate discharge from the hospital. Related to this problem is the need to ensure that eligibility waiting periods are waived so that a patient doesn't die before Medicare coverage begins.

o We strongly oppose the Administration's proposal to cap Federal Medicaid payments which, combined with the increasing costs of services to AIDS patients, will result in an intolerable burden on the State. The State currently estimates a $400 million Medicaid shortfall between projected costs and the proposed cap. This shortfall will exacerbate the problem of providing adequate services to persons with AIDS.

o As we move towards Medicare DRG based rates, it is critical that adequate reimbursement be provided to reflect the level and intensity of services required by AIDS patients.

In summary, the State recommends that Medicaid, Medicare, and SSI coverage be modified to support a wider range of medical and related services. If we want to prevent the unnecessary hospitalization of AIDS patients, federal support for various levels of care such as hospice, home health and other nontraditional services must be provided.

Mr. WAXMAN. Thank you very much for your statement.

Ms. Matthews, in the three examples you gave in your testimony, you talk about home health, home nursing, and home hospice services. Has it been easy for you to find health care agencies or personnel who will provide this care to your policyholders? Have you just called a home health agency and had them send someone over? Or do you have to do special work to get care to an AIDS patient?

Ms. MATTHEWS. Up until recently it has been quite difficult to get people to service AIDS victims. We find that there is a lack of education, probably a lack of general awareness of how the disease is transmitted. A lot of health care professionals have elected not to service these patients.

The little child that I mentioned here, that particular agency did a reeducation program about 6 months to 1 year ago to all of their staff, including the nursing personnel and other disciplines in their agency on AIDS, how it is transmitted, and about the disease. They also prepared special video tapes and cassette tapes for their staff so that they could go home and watch these tapes and learn more about the disease process.

It is still voluntary in the health care profession as to whether you elect to service these patients or not.

Mr. WAXMAN. You are a nurse yourself. If Medicaid were to pay for nonhospital care for AIDS today, would it take demonstration projects or in-service training to get an adequate number of nurses to work with AIDS patients outside the hospital?

Ms. MATTHEWS. I think there would need to be an extensive education process, yes.

Mr. WAXMAN. Has Transamerica done its own studies of in-hospital versus out-of-hospital care for AIDS patients?

Ms. MATTHEWS. Yes.

Mr. WAXMAN. We would like to have you submit that study for us, if you would.

Ms. MATTHEWS. We did it—when I say yes, it's yes for all patients. We have done a cost of home care versus a cost of hospitalization. We have done a pilot on that.

Mr. WAXMAN. We would appreciate it if you could give to us for the record the information from that pilot project.

Ms. MATTHEWS. Certainly.

Mr. WAXMAN. Thank you.

Mr. Rosen, has New York done an analysis of the cost of AIDS care and who pays for it?

Mr. ROSEN. New York is currently doing that. We can send you a copy of our analysis. It should be done in the next few weeks, sir.

Mr. WAXMAN. We would like to hold the record open and receive that from you.

Has the State concluded that the provision of nonhospital care for AIDS and ARC is useful?

Mr. ROSEN. Absolutely. And that's the direction that we are going in.

Mr. WAXMAN. Will such services be available spontaneously, or will it require some government or professional intervention?

Mr. ROSEN. No, none of this happens by itself. New regulations have gone into place in order to force hospitals to—not force hospi-

tals, but we sent out request for proposals to see which hospitals will be the first hospital, 15 to be designated AIDS hospitals. This means they would get a higher reimbursement rate. But this is not just happening. This is something that the State has to do. This is something that the State has to monitor.

The State is going to need some help from the Federal Government because we are not going to be able to pay for everything.

I would say the single biggest problem we are facing in putting together this comprehensive model is with some of the nontraditional services. We have got a number of different risk groups in New York City and New York State that California doesn't. And they are going to need special types of crisis intervention and services.

Now, we've got the agencies, either new ones that we have developed or old ones, that can provide those services. But we don't have ways to reimburse them. And that's what we are looking to the Federal Government for help for.

The other stuff we're willing to pay for.

Mr. WAXMAN. Thank you very much.

Mr. Dannemeyer.

Mr. DANNEMEYER. Ms. Matthews, how did this 65-year-old male get AIDS?

Ms. MATTHEWS. I have no idea, sir.

Mr. DANNEMEYER. Did I understand correctly that that child that was born in 1982 had accumulated costs of $332,000 so far?

Ms. MATTHEWS. That was during the period of time, sir, that he was insured with us. He was transferred to us, as I said, in 1984. So, he was already age 2. And he had been diagnosed as having AIDS at age 9 months.

Mr. DANNEMEYER. Mr. Rosen, I don't know whether you in your capacity of working in this health care field in New York State have anything to do with it, but can you tell us whether or not New York City has taken action to shut down the bathhouses that exist in that city?

Mr. ROSEN. New York City operates in some aspects under New York State. New York City has closed down some bath——

Mr. DANNEMEYER. Do you mean you're not connected with New York City?

Mr. ROSEN. Well, no, this is the New York State Health Department.

Mr. DANNEMEYER. You work for the New York——

Mr. ROSEN. I work for New York State. If you ask me to talk for New York City, it's very difficult; and I would rather not.

Mr. DANNEMEYER. It's another State. Is that what you're saying?

Mr. ROSEN. Well, I am not saying it's another State, but they have their own—we've let them have their jurisdiction in some cases.

Mr. WAXMAN. It's called federalism.

Mr. DANNEMEYER. We're all concerned, I think, as citizens in the country about taking care of these victims of AIDS. There's no question about that. But I think we should also have some concern about stopping the transmission of AIDS. That's why I asked about bathhouses——

Mr. ROSEN. I think that there's more to that question than just bathhouses. I think the bathhouses are the least of the problem. I think that the biggest problem is general education for everybody, risk groups and nonrisk groups. We spent millions of dollars on this. And when we got to a point a few months ago where we felt that things were getting out of hand, the media were talking about children in schools every day, the Governor became very upset and asked our institute to publish a book for him called One Hundred Questions. We have sent out hundreds of thousands of these now, not only to the population, whoever wants it, but also to radio and TV stations. The Governor himself has gotten on TV.

Basically, we are doing a somewhat effective job of education. I am not going to say we are terrific at it, because we have the same problem—I think we have the same problems that the Federal Government has, to be honest with you. And I don't want to be anything other than honest. I think the biggest problem in the State and in this country is that we haven't been able to be honest in terms of telling people how to stop the spread of the disease. And that means we have to talk about some sensitive things on television and on radio. People get a little bit flustered. And I think on both the State, city, and Federal levels we haven't been able to do the right type of thing because different groups don't want us to talk about such things on the media.

I understand that. But I think that in the long run that is going to be detrimental to the health of the country.

Mr. DANNEMEYER. So, I guess the answer is New York City still hasn't shut down the bathhouses.

Mr. ROSEN. OK, if you're going to press me on that point, New York City follows a regulation that was approved by the, or put out by the public health council, which is sort of the board of health for the State health department, which wrote a document of what it felt to be unsafe sex, sexual practices. New York State—New York City enforced those regulations in the way that it saw fit and did close down some bathhouses.

Mr. DANNEMEYER. But there are still some operating there, is that right?

Mr. ROSEN. Well, I don't know, sir, I don't follow bathhouses.

I really don't know the answer to that question, if there are some running, because I don't know that much about the bathhouses in New York City. I know that New York City closed down one or two of them?

My responsibility is all of New York State.

Mr. DANNEMEYER. These safe sex practices, does that mean that we have set up monitors in bathhouses to ensure that safe sex be practiced in them?

Mr. ROSEN. I am not sure what New York City has done in terms of monitoring. Why don't you ask someone from New York City to come here?

Mr. DANNEMEYER. Well, it's very difficult for some of us to get hearings before this subcommittee. I haven't figured out the mysterious quest yet. From time to time I make the request of my distinguished chairman, and I am still looking for a response.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Ms. Matthews and Mr. Rosen. I want to commend you on your testimony. It has been very helpful to us as we look at this aspect of the AIDS epidemic. Of course, we will be continuing to look at other aspects of it as well.

That concludes our business before the subcommittee. We stand adjourned.

[Whereupon, at 12:05 p.m., the hearing was adjourned.]

66-764 (160)